

**Patient Innovation**  
SHARING SOLUTIONS, IMPROVING LIFE

# ***CELEBRATING 3 YEARS OF PATIENT INNOVATION***

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Report 2014-2017



2014

***CELEBRATING  
3 YEARS OF  
PATIENT  
INNOVATION***

2017





*To all patients, caregivers,  
and collaborators that made  
this journey possible. Thank you.*

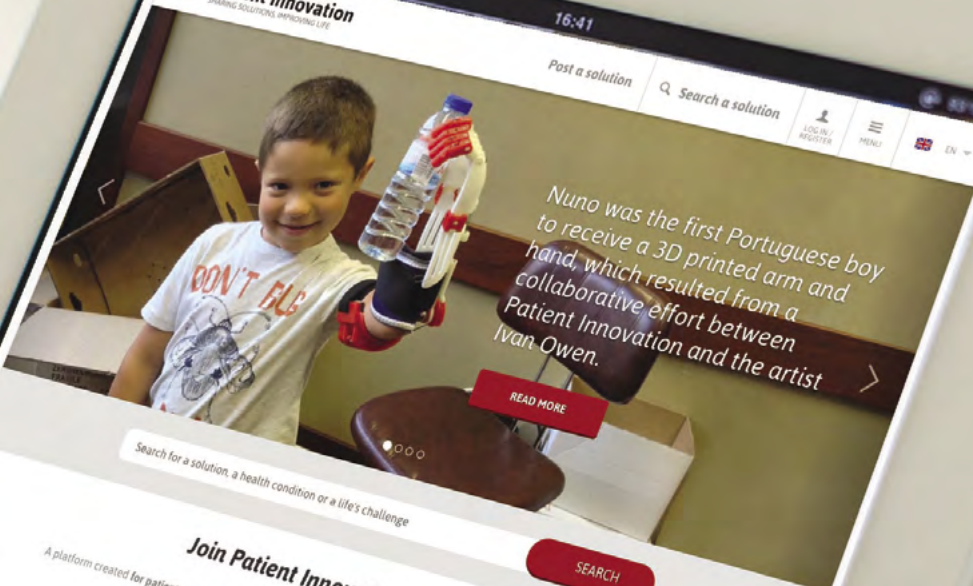
[patient-innovation.com](http://patient-innovation.com)

[facebook.com/PatientInnov](https://facebook.com/PatientInnov) • [twitter.com/PatientInnov](https://twitter.com/PatientInnov) • [youtube.com/c/patientinnovationpi](https://youtube.com/c/patientinnovationpi)

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Nuno was the first Portuguese boy to receive a 3D printed arm and hand, which resulted from a collaborative effort between Patient Innovation and the artist Ivan Owen.

[READ MORE](#)

Search for a solution, a health condition or a life's challenge

## Join Patient Innovation community

A platform created for patients and those who care about them to share and access useful solutions to cope with their diseases.



### SEARCH

See solutions from others with similar challenges as yours and give your feedback!



### POST

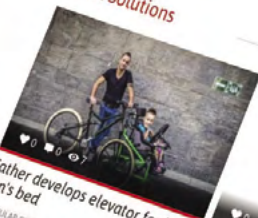
Do you have a solution? Great! Post it on Patient Innovation and help improving lives.



### FORUM

Every great solution starts with a simple idea. Discuss how to turn your and others ideas into solutions.

### Latest Solutions



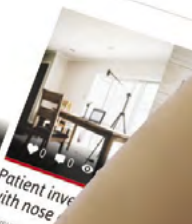
**Father develops elevator for his son's bed**

MUSCULAR DYSTROPHY   PHYSICAL DISABILITY  
CEREBRAL PALSY   ARTHRITIS



**Man invents glasses for his visually impaired sisters**

VISUAL IMPAIRMENT   MACULAR DEGENERATION  
DIABETIC RETINOPATHY   STARGARDT'S DISEASE



**Patient invents nose**

PHYSICAL DISABILITY  
CARPAL TUNNEL SYNDROME



# *Our Project*

*The Patient Innovation project is an international, multilingual, non-profit platform, and social network that connects patients and caregivers, and enables the sharing of their solutions. If not shared, these strategies, treatments, devices, and knowledge would probably remain unknown to many patients, not fulfilling their potential to change the lives of others.*

*We want to be the means to that sharing. We want to help people change their own lives and the lives of many others through sharing.*



# *Letter from the Team*



## Dear all,

Patient Innovation was developed in 2014 with the purpose of sharing and helping to improve lives. In these three years we have managed to reach a wide audience. We celebrated patients and caregivers through the 1<sup>st</sup> Patient Innovation Awards in July 2015 and the 2<sup>nd</sup> edition of the Patient Innovation Awards in November 2016.

The number of solutions shared on our platform has been increasing every day. In 2017, we reached a new milestone: 750 solutions on the platform! Through sharing, we all grow. Each solution shared becomes a piece of the Patient Innovation heart.

It has been three years since we began working to break down economic, geographical, and language barriers, by improving our platform each day, providing more solutions, and increasing awareness. By doing so, we are helping to improve the lives of members of the Patient Innovation community worldwide.

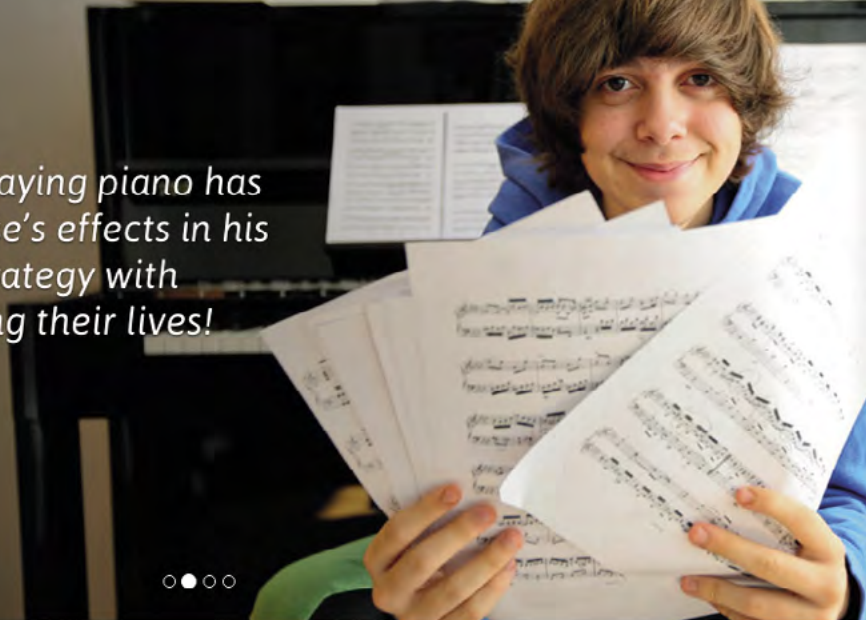
All the best from the Patient Innovation team.

### 01

*From left to right: Salomé Azevedo, Ana Duarte, Maria João Gonçalves, Miguel Amaral Nunes, Pedro Oliveira, Patrícia Rodrigues, Tina Drusay, Helena Canhão, Leid Zejnilovic and João Pedro Covas.*

Diogo found out that playing piano has slowed down the disease's effects in his hands. He shared his strategy with other patients, improving their lives!

READ MORE



Search for a solution, a health condition or a life's challenge

SEARCH

## Join Patient Innovation community

A platform created for patients and those who care about them to share and access useful solutions to cope with their diseases.



### SEARCH

See solutions from others with similar challenges as yours and give your feedback!



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Do you have a solution? Great! Post it on Patient Innovation and help improve lives.



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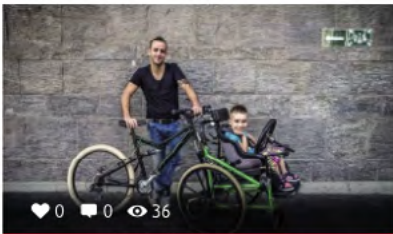
Every great solution starts with a simple idea. Discuss how to turn your and others ideas into solutions.

## Latest Solutions



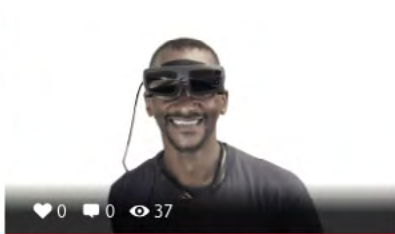
Father creates stabilizer for his son

DIPLEGIA   PHYSICAL DISABILITY   CEREBRAL PALSY  
ARTHRITIS   WALKING   EATING (EAT+DRINK)



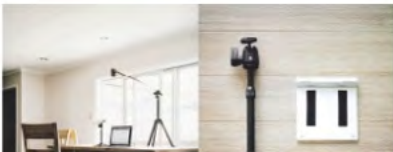
Father develops elevator for his son's bed

MUSCULAR DYSTROPHY   PHYSICAL DISABILITY  
CEREBRAL PALSY   ARTHRITIS



Man invents glasses for his visually impaired sisters

VISUAL IMPAIRMENT   MACULAR DEGENERATION  
DIABETIC RETINOPATHY   STARGARDT'S DISEASE



# *Patient* *Innovation* *Platform*



*“This is an outstanding social media use that should help many disadvantaged people.”*

— **Sir Richard Roberts**

CHIEF SCIENTIST, NEW ENGLAND BIOLABS  
NOBEL LAUREATE IN PHYSIOLOGY OR MEDICINE 1993  
PATIENT INNOVATION ADVISORY BOARD MEMBER

# *The purpose of the Patient Innovation Platform*

This project is the result of a multidisciplinary research, which involves the areas of management, health sciences, engineering, and law. The investigation started in 2011, led by CATÓLICA-LISBON School of Business & Economics, in partnership with the MIT, Sloan School of Management, and the Carnegie Mellon University.

Currently, in Portugal, the project also includes the partnership of the Instituto de Medicina Molecular, the Faculty of Medicine University of Lisbon and Nova Medical School of New University of Lisbon. The project, founded and led by Prof. Pedro Oliveira and Prof. Helena Canhão, has received support from several reputed members of the scientific community, including Nobel Laureates, notable academics of several scientific fields, patients and patient associations of several diseases, from all around the world.

However, it was then discovered that these solutions, developed by patients, caregivers, and collaborators, weren't being shared.

**Founded and led by Prof. Pedro Oliveira and Prof. Helena Canhão**

It became clear that there was a need to create an online platform that made the diffusion of these solutions possible.

And from this, Patient Innovation was born.

**An open platform for patients (those who develop solutions for themselves), caregivers (those who develop solutions for loved ones), and collaborators (those who develop solutions for someone outside their circle of family/friends) of any disease and geography.**

The problem or challenge experienced by a user (patient, caregiver, or collaborator) may be similar to that of many other patients and caregivers.

So the solution developed to solve this problem could be applicable to many other people. Posting and sharing your solution will contribute to updating and improving this platform, helping others to solve their own challenges.

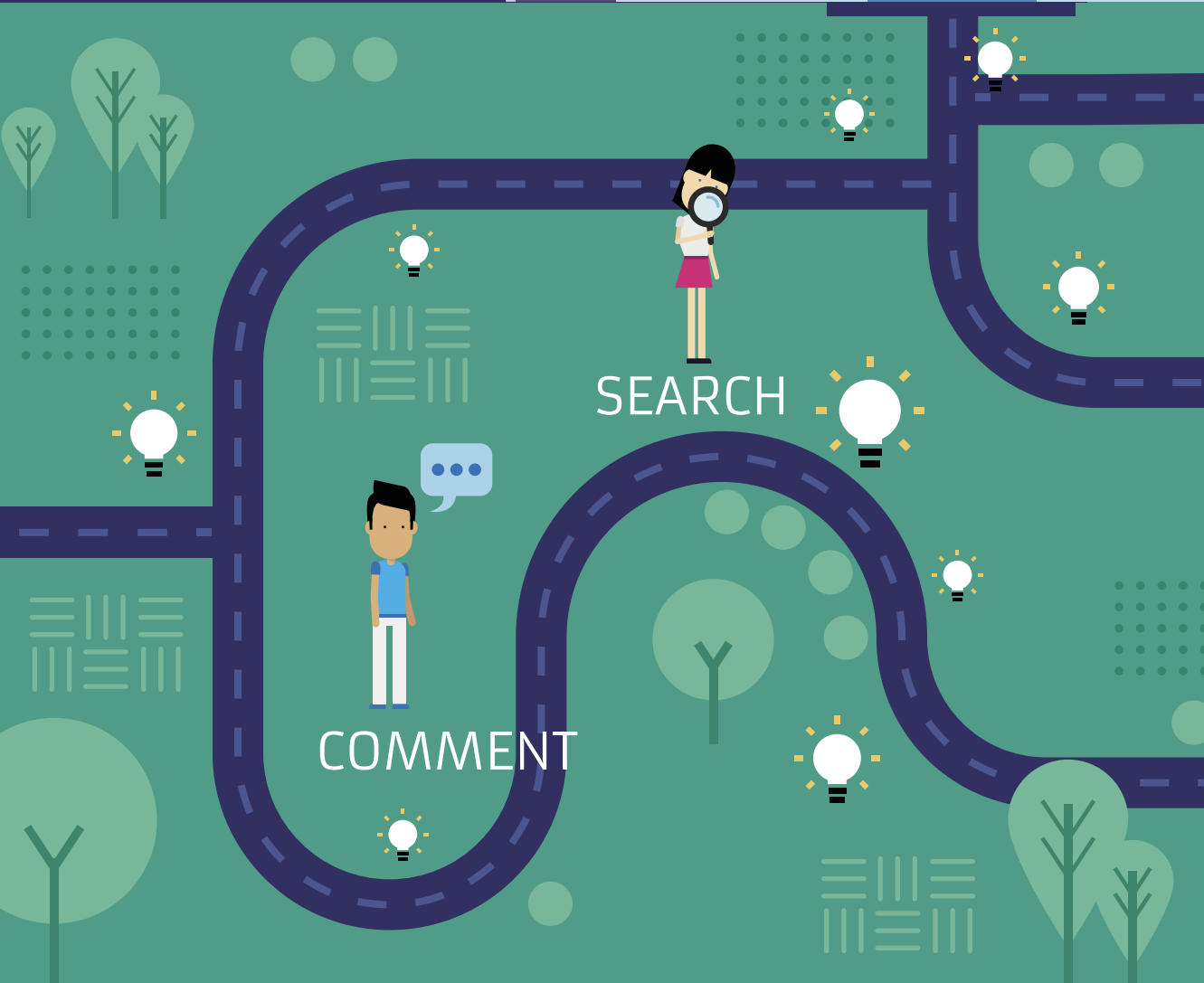
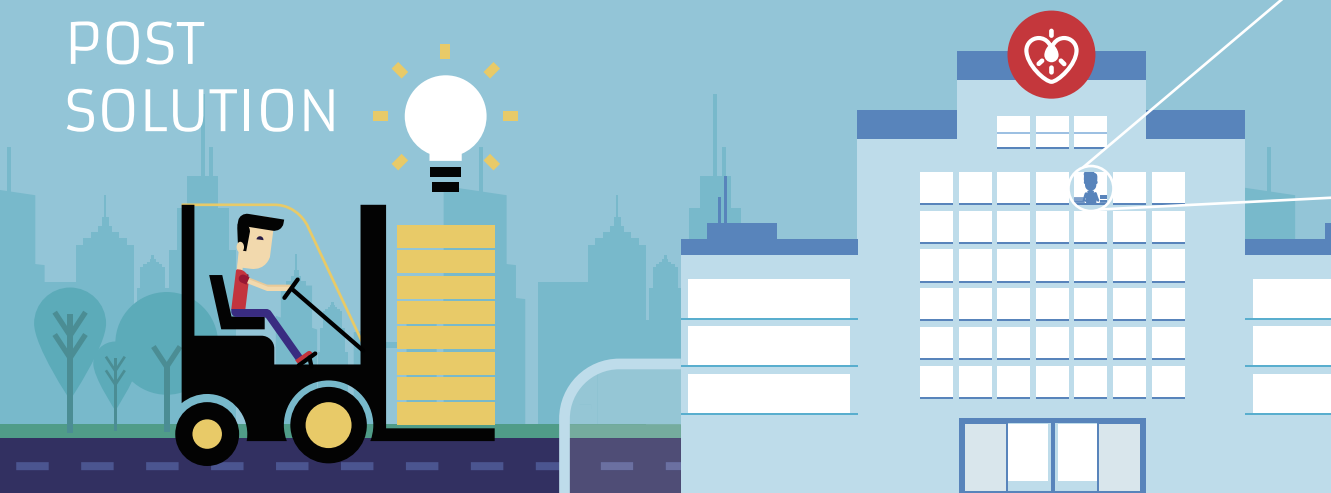


**Anyone  
can join the  
platform**



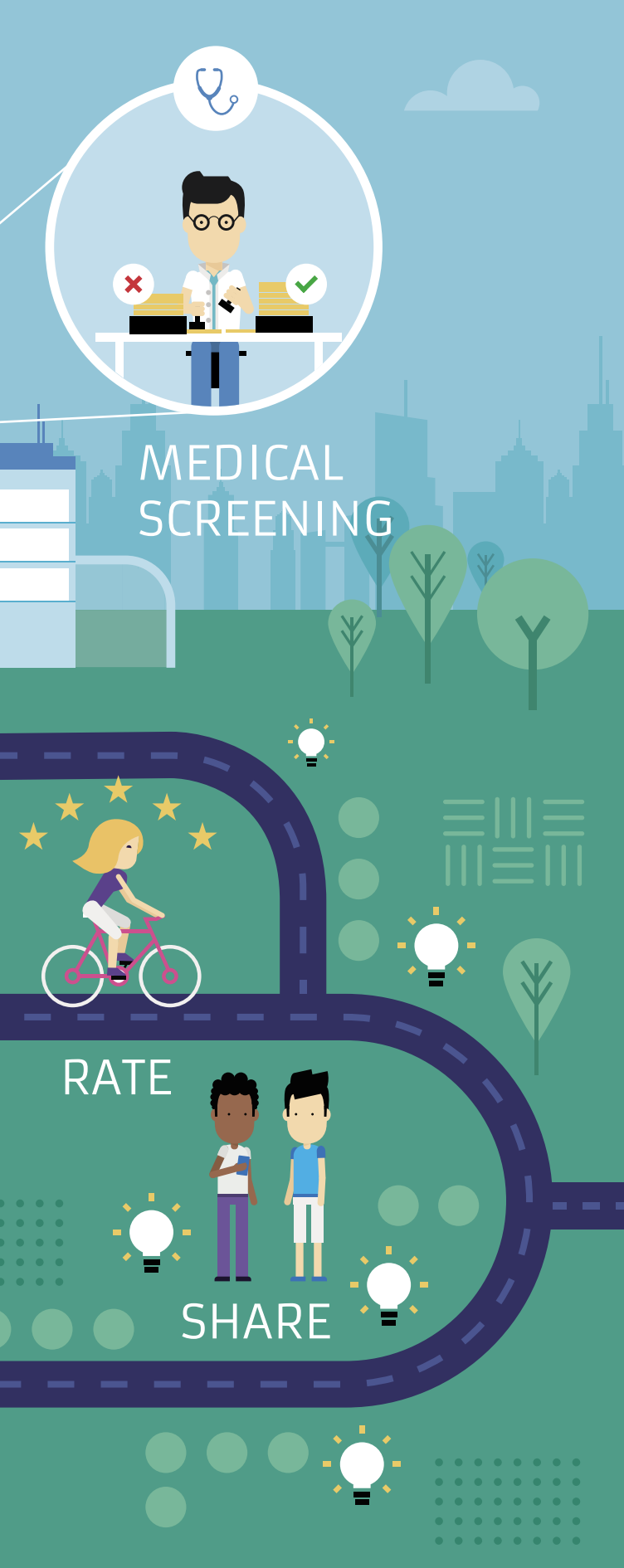
“...there was a need to create an online platform that made the diffusion of these solutions possible. And from this, Patient Innovation was born”

POST  
SOLUTION



SEARCH

COMMENT



## 1 / Patient Innovation Platform

### *The purpose of the Patient Innovation Platform*

After registering, users have full access to all patient communities, where they may **share any solutions they have developed with others**, as well as **browse solutions and strategies that other users have created and shared with the community**.

**Another feature that makes this platform unique is its medical screening.**

All of the solutions undergo a screening process that identifies and removes posts deemed offensive or inappropriate, for the purpose of commercial trade, that do not qualify as a proposal, that involve drugs, chemicals or biologics, that consist of invasive devices, or that are visibly and intrinsically dangerous.

Many solutions are of a practical nature and may not require scientific validation. However, this does not disregard their importance in facilitating the day-to-day lives of patients and caregivers.

Furthermore, the user community, which may include **patients, health professionals, and other individuals**, will **provide feedback through comments and informal ratings to the proposed solutions**.

# How it works



We have envisioned a platform that allows anyone to explore the world of patients, caregivers and collaborators that create solutions to overcome challenges presented by a health condition.

To start using the Patient Innovation platform, simply go to ↓

<https://patient-innovation.com>

Through this link, you will find information that will help you become part of this incredible community. Nevertheless, here is a sneak peek of what you can do.



# 1. SEE WHAT'S HAPPENING

All published solutions are grouped into categories, making everything related to the same topic easier to find. You can explore shared solutions through our **six categories** (↓) or through keywords.

## CONDITION

Solutions sorted by condition.  
Ex.: What solutions were developed for individuals with paraplegia?

## SYMPTOM

Solutions sorted by symptom.  
Ex.: Are you looking for solutions for unbearable headaches?

## LOCATION

Solutions related to a specific part of the human body.  
Ex.: Do you have some trick to reduce hand tremor?

## ACTIVITIES

Solutions sorted by activities.  
Ex.: Are you looking for solutions to overcome some obstacles inherent to a specific activity (walking, eating, showering...) ?

## DEVICES

All the devices sorted by type (wheelchairs, apps, 3D printed devices, etc.)

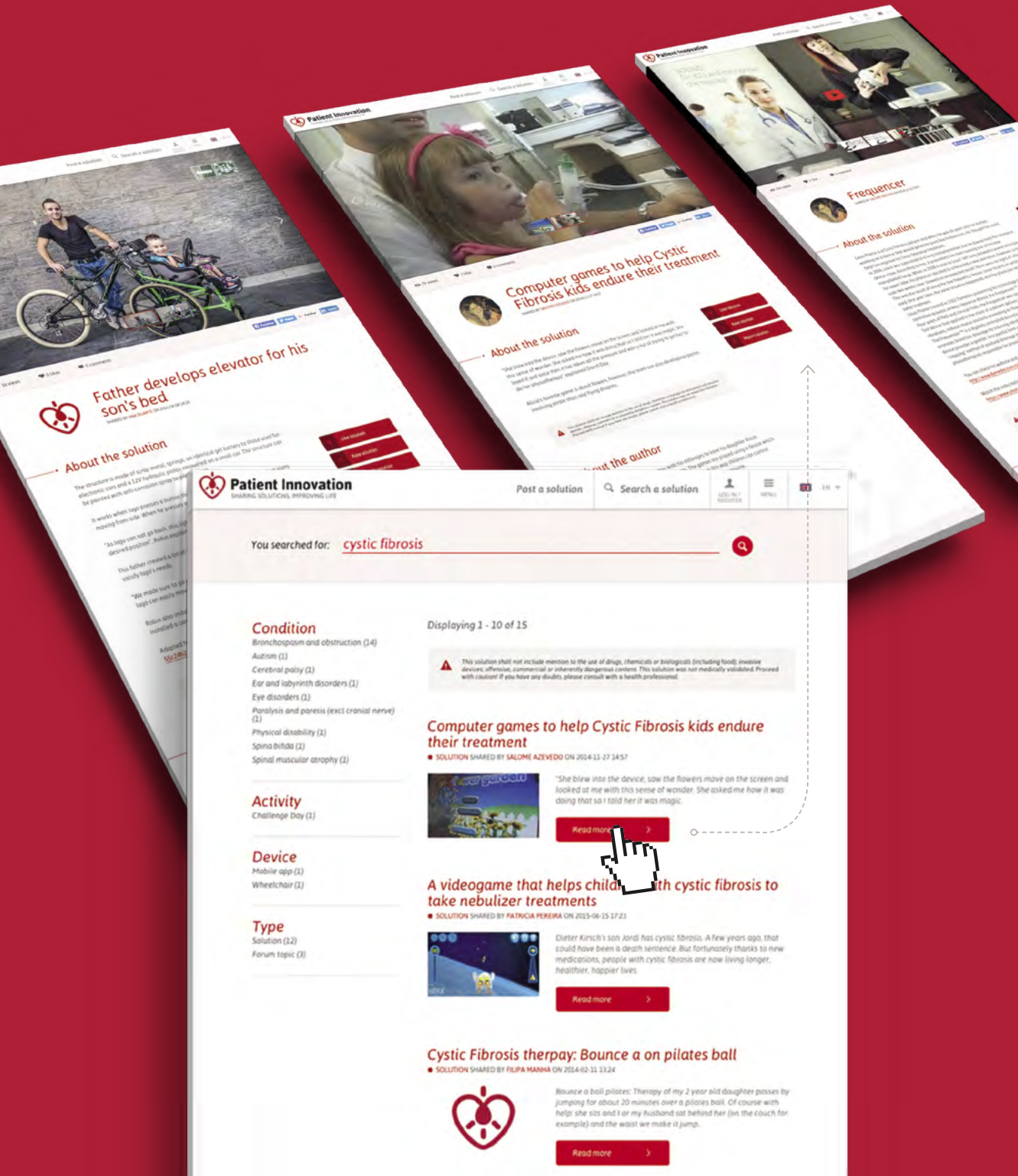
## THERAPY

Solutions to overcome some problems during therapy.  
Ex.: The backpack developed by an 11-year-old girl, Kylie Simonds, to help her during chemotherapy.



## 2. DISCOVER THE LATEST SOLUTIONS

Get inspired! Look for the latest solutions and discover what patients and caregivers have been doing



### 3. POST YOUR OWN SOLUTION

Post the solution you have developed. Don't worry if it seems simple; as long as it has helped you overcome an issue, it is considered a solution. People who suffer from the same problem will be grateful!



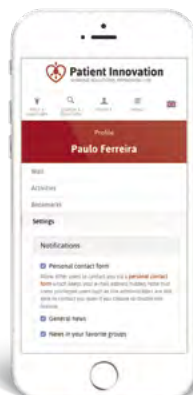
### 4. BE SOCIAL

Comment and help others improve their solutions by giving your feedback! Share your own solution or the solutions of others on Facebook, Twitter or YouTube!



### 5. MANAGE FAVORITES

Once you register, you can bookmark the groups of diseases that interest you the most. You can also set up notifications to receive updates from your favorite groups.



# Launch Event

Our platform and research initiative was publicly presented at the Patient Innovation Launch Event, held at CATÓLICA-LISBON in Portugal, on February 7<sup>th</sup> 2014

This event brought together patient innovators, scholars, and supporters of our international, non-profit Patient Innovation platform.

We had the pleasure of featuring a group of patients, caregivers and collaborators who shared their own obstacles and amazing solutions, such as Tal Golesworthy ("the man who fixed his aorta"), Ana Luísa Vaz ("the type 1 diabetes girl who, against all odds, runs marathons"), Ivan Owen ("the artist who prints fingers and hands in a 3D printer"). Along with them, some important members of the scientific community, such as Prof. Eric von

Hippel, Sir Richard Roberts and Harry DeMonaco gave remarkable talks. An incredible day where patients, caregivers and collaborators were celebrated as innovators and the motivation behind their creations were highlighted.

Participants from several different fields came together to discuss the *status quo* of technology in healthcare and the importance of empowering people to create and share their own solutions.

## 02 KEYNOTE SPEAKERS

*Some of the launch event's keynote speakers, from left to right: Francisco Veloso, Glória Garcia, Salvador Mendes de Almeida, Tal Golesworthy, Ana Luísa Vaz, Louis Plante, Diogo Lopes and Joaquina Teixeira.*



02



03

## 03 DIOGO LOPES

*A young pianist who suffers from Charcot Marie Tooth disease, who had the idea for the development of thermal pockets, which were created by students from JUNITEC.*



04

#### 04 SIR RICHARD ROBERTS

1993 Nobel Prize Laureate in Physiology or Medicine, and Patient Innovation Advisory Board member.

# Platform evolution

Patient Innovation has made some significant changes to its platform since its launch in 2014.

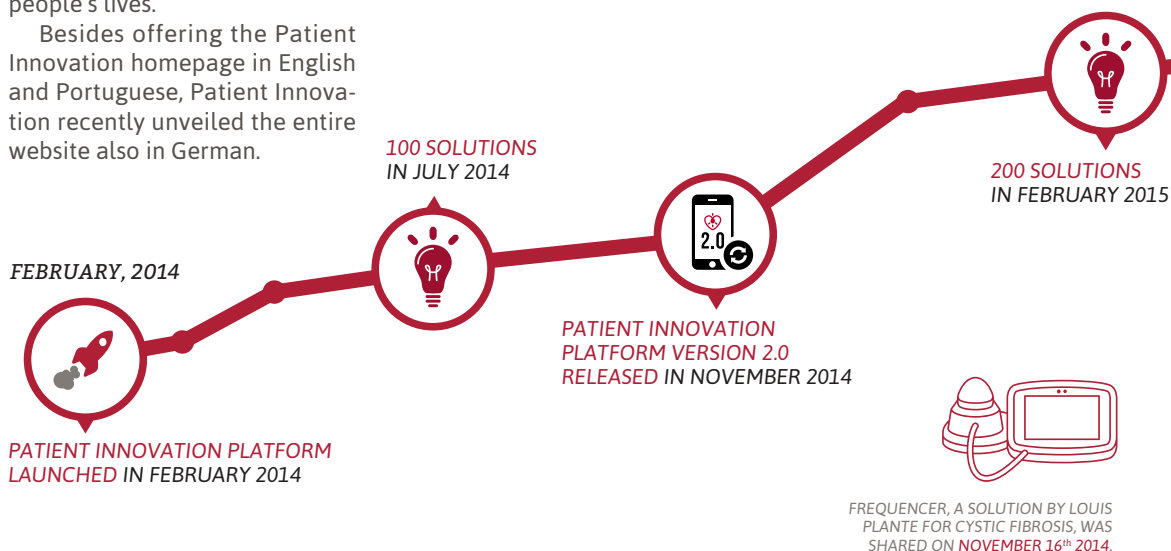
What started as an academic repository of medical innovations developed by patients, caregivers, and collaborators, has grown into a multilingual platform that encourages people from all around the world to post, share, discuss and evaluate solutions, tips and adaptations that make life more comfortable and happier for the community. Patient Innovation has become a centralized place for posting and sharing innovative solutions that help improve people's lives.

Besides offering the Patient Innovation homepage in English and Portuguese, Patient Innovation recently unveiled the entire website also in German.

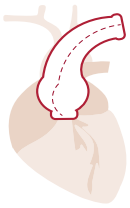
**In January 2016, Patient Innovation achieved another milestone with 600 live solutions developed by members of the community, and curated by the Patient Innovation medical team**

The team is always working to improve the designs of other features. Updates usually come out slowly and at a small scale, with the community getting the first taste of new features before they go live.

In January 2016, Patient Innovation achieved another milestone: 600 live solutions developed by members of the community, and curated by the Patient Innovation medical team. With the help of our community, the Patient Innovation database is growing every day.



*What started as an academic repository of medical innovations developed by patients, caregivers and collaborators has grown into a multilingual platform that encourages people from all around the world to post, share, discuss and evaluate solutions, tips and adaptations that make life more comfortable and happier for the community*



TAL GOLESWORTHY'S SOLUTION EXOVASC® FOR MARFAN SYNDROME HAS BEEN IMPLANTED SUCCESSFULLY IN MORE THAN 100 PATIENTS

300 SOLUTIONS IN JUNE 2015



500 SOLUTIONS IN DECEMBER 2015



600 SOLUTIONS IN APRIL 2016

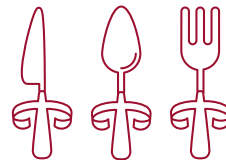


PATIENT INNOVATION PLATFORM VERSION 3.0 RELEASED IN NOVEMBER 2016



750 SOLUTIONS IN JULY 2017

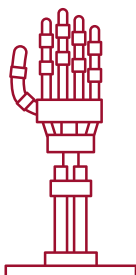
3<sup>rd</sup> PATIENT INNOVATION AWARDS, NOVEMBER 28<sup>th</sup> 2017



FLATWARE FOR DISABLED PEOPLE WAS ONE OF THE FIRST SOLUTIONS OF 2016, SHARED IN PATENT INNOVATION PLATFORM ON JANUARY 11<sup>th</sup> 2016

**+100**

solutions related to 3D printing technology



Share your solutions now at [patient-innovation.com](http://patient-innovation.com)



# *Patient* *Innovation* *Awards*



*“I firmly believe it is an initiative at the cutting edge of research and innovation, and a project with the potential to improve the lives of many around the world”*

**— Francisco Veloso**

PROFESSOR, FORMER DEAN OF CATÓLICA-LISBON SCHOOL OF BUSINESS & ECONOMICS  
DEAN OF IMPERIAL COLLEGE BUSINESS SCHOOL  
PATIENT INNOVATION SUPPORTER

# *The 1<sup>st</sup> Patient Innovation Awards*



### Patient Innovation is all about empowering patients, caregivers, and collaborators, by highlighting their valuable knowledge and experience

We want to keep motivating our community to be creative and innovative, and to share their solutions with each other. That is why we have created the Patient Innovation Awards, where the Patient Innovation team celebrates the achievement and contribution of patients, caregivers and collaborator innovators, each year.

These awards provide the opportunity to recognize any patient, caregiver or collaborator who has developed a solution that helps cope with a health condition or disease, and posted it on the Patient Innovation platform.

The Patient Innovation Awards honor innovators in three separate categories according to their solutions' novelty and relation with need:

#### • PATIENT INNOVATION AWARD

Innovation developed by a patient, improving his/her own health condition;

#### • CAREGIVER INNOVATION AWARD

Innovation developed by a caregiver, to help improve the health condition of a loved one;

#### • COLLABORATOR INNOVATION AWARD

Innovation developed by a collaborator to help improve the health condition of someone outside their circle of family or friends.

The Patient Innovation team undertook an initial screening of more than 200 innovations that were considered eligible, and then made a short list of ten innovations per category.

This list was elaborated based on the novelty, potential and impact of the solution in helping others with the same condition to manage their care process.

Two additional criteria were taken into account regarding the innovator: the recognition as an inspirational role model to society, and the commitment devoted to diffuse the solution, thus empowering others. The final decision was made by the Advisory Board who, when faced with outstanding solutions, could not restrict themselves to one winner per category and awarded a total of six winners, which were announced on February 6<sup>th</sup> 2015 and the ceremony took place on July 13<sup>th</sup> 2015.

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#### Sponsors:



# *The winners list, based on the criteria described before, resulted as follows:*

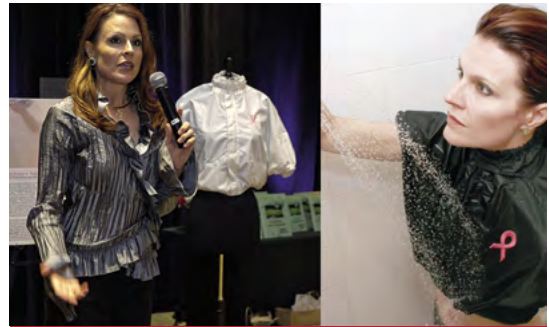


**Louis Plante (Canada)**  
THE FREQUENCER™

Louis Plante\* suffers from Cystic Fibrosis, which leads to an increase in the risk of pulmonary infection, resulting from changes in secretion of mucus-producing glands. Louis would previously spend four hours a day in kinesiotherapy (alternate beats in the chest and back) to reduce the problem, until one day, during a concert, Louis noticed that the vibration produced by the speakers had a positive effect. Based on his experience in electronics, Louis developed the Frequencer™, a device that produces sound waves, which helps to clean the lungs, by creating low energy resonant vibrations (acoustics), reducing mucus viscosity and allowing an increased mucus flow in patients with Cystic Fibrosis.

\* Louis Plante has passed away on April 8<sup>th</sup> 2017, but his legacy will live on all patients with Cystic Fibrosis that he helped. Louis will be always remembered.

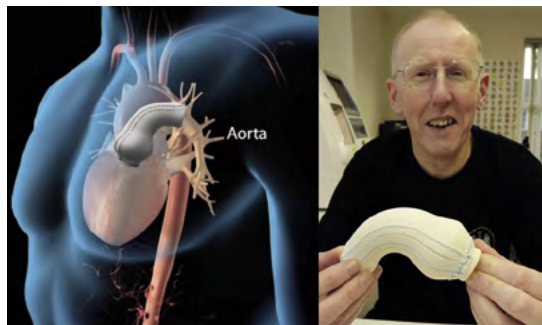
IN CATEGORY: **PATIENT**



**Lisa Crites (USA)**  
THE SHOWER SHIRT™

Lisa Crites was diagnosed with breast cancer. After having a mastectomy, she was told not to wet the suture area in order to avoid infection in the drains of insertion sites. This made showering difficult. That was when Lisa created a water proof shirt, The Shower Shirt™, helping other patients suffering from the same problem to shower normally, living with this condition with dignity. The Shower Shirt™ has already been approved by the FDA, and is now available in 36 countries.

IN CATEGORY: **PATIENT**



**Tal Golesworthy (UK)**

THE EXOVASC®

Tal Golesworthy, suffering from Marfan Syndrome, needed cardiac surgery and would be treated with anticoagulants for the rest of his life. He used his professional experience in engineering and his plumbing knowledge to design, with the help of his doctors, an external support for the aorta root - Personalized External Aortic Root Support. Since this support was put in his heart, in 2004, the same technique has been used in more than 100 patients to prevent rupture of the aorta.

IN CATEGORY: **PATIENT**



**Debby Elnatan (Israel)**

THE UPSEE™

Debby's youngest son was born with cerebral palsy. Despite not being able to move or participate in family walks, Debby didn't give up. She tried several ways to "connect" her son to herself, which led to Upsee™. With the Upsee™, her son is able to "walk" like any other child, and can now participate in the family activities. Upsee™ helps children with similar conditions to "walk" and participate in social events.

IN CATEGORY: **CAREGIVER**



**Joaquina Teixeira (Portugal)**

HELIUM BALLONS

Joaquina's son, Gonçalo, suffers from Angelman Syndrome, a disease characterized by developmental delay, inability to speak, convulsions and psychomotor problems. Despite being six and able to walk, her son refused to stand up. One day, at a party, Joaquina noticed that the helium balloons on the ceiling were getting the boy's attention, making him try to grab them and, by doing so, he was standing up. On that very day, Joaquina put helium balloons all over her house and watched her son jump and walk, trying to grab the balloons.

IN CATEGORY: **CAREGIVER**



**Ivan Owen (USA)**

3D PRINTED HAND

Ivan Owen, an artist who makes entertainment products, posted a video on Youtube featuring a "mechanical hand". A Southern African carpenter, who lost some of his fingers while working in his shop, contacted him and asked if Ivan could help him design and make a low cost prosthetic hand. Ivan accepted the challenge and started making low cost prosthetic hands also for children. Later on, he shared his digital files to make these hands in 3D printers. His work has inspired a large and growing number of volunteers and creators that are now trying to make a difference (e.g. e-NABLE).

IN CATEGORY: **COLLABORATOR**

## 2 / Patient Innovation Awards

*The 1<sup>st</sup> Patient Innovation Awards*

# *“Embrace open innovation of all kinds”*

› Carlos Moedas

EUROPEAN COMMISSIONER FOR RESEARCH,  
SCIENCE AND INNOVATION

The six award winners had time on stage to explain their own story, highlighting the need and the motivation behind their solution to a full auditorium.

The event received great feedback from the audience, keynote speakers and winners, as well as a strong presence in the media.

Carlos Moedas, European Commissioner for Research, Science and Innovation, Prof. Eric von Hippel from MIT and the six award winners, from Canada, the USA, Israel, United Kingdom and Portugal were the keynote speakers. The Patient Innovation Awards received the High Patronage of His Excellency The President of the Portuguese Republic.

The Commissioner congratulated the Patient Innovation project for inspiring Europe to “embrace open innovation of all kinds”.

In his speech, he had kind words for the finalists remembering the importance of their innovations for society.

Prof. Eric von Hippel, representing the Patient Innovation Advisory Board, gave an incredible and inspiring talk about how to better understand the power of citizen innovation and the consequential effects of adopting and diffusing user-driven solutions.

05



06

## 2 / Patient Innovation Awards

### *The 1<sup>st</sup> Patient Innovation Awards*



#### **05 AWARD CEREMONY**

*The 1<sup>st</sup> Patient Innovation Awards ceremony at Fundação Calouste Gulbenkian, Lisbon, on July 13<sup>th</sup> 2015.*

#### **06 OPENING**

*Pedro Oliveira, Patient Innovation project founder and leader, opening the awards ceremony.*

#### **07 PROF. ERIC VON HIPPEL AND CARLOS MOEDAS**

*Prof. Eric von Hippel, Patient Innovation Advisory Board member and Carlos Moedas, European Commissioner for Research, Science and Innovation.*

#### **08 THE AWARDS**

*The Patient Innovation Awards.*

#### **09 FAMILY PORTRAIT**

*Patient Innovation Awards ceremony group portrait.*

# *The 2<sup>nd</sup> Patient Innovation Awards*



# *The 2<sup>nd</sup> Patient Innovation Awards ceremony took place on November 10<sup>th</sup> 2016 during the Web Summit in the Meo Arena, Lisbon*

The success of the 1<sup>st</sup> Patient Innovation Awards encouraged the Patient Innovation team to go for the second edition of the ceremony. The deadline to submit an innovative solution for the 2<sup>nd</sup> edition was January 15<sup>th</sup> 2016.

These new winners were publicly announced in April 2016 and a new category was added: Serial Patient Innovator, for a patient who develops several solutions. The 2<sup>nd</sup> Patient Innovation Awards ceremony took place on November 10<sup>th</sup> 2016 during the Web Summit in the Meo Arena, Lisbon.

The Web Summit is Europe's largest and most important technology market place with 53 000 attendees from 150 countries.

After meeting with the Advisory Board on January 28<sup>th</sup> 2016, the Patient Innovation team selected seven innovators as the winners of the 2<sup>nd</sup> Patient Innovation Awards.

---

## Sponsors



The background of the image shows a stage setup for an event. On the left, a green backdrop features the 'HealthConf' logo, which consists of a heart shape with a pulse line. To the right, a large screen displays a blue and yellow geometric design with the 'Health' logo. Below the screen, a row of 'Web Summit' logos is visible. The foreground is dominated by a large red diagonal shape that serves as a background for the white text.

*The 2<sup>nd</sup>  
Patient  
Innovation  
Awards @  
Web Summit*



HealthConf

HealthConf

web summit

web summit

web summit

web summit

web summit

web summit

### The 2<sup>nd</sup> Patient Innovation Awards Ceremony was held at the HealthConf, on November 10<sup>th</sup> 2016

The Web Summit brought a lot of people to Lisbon, from November 7<sup>th</sup> to November 10<sup>th</sup> 2016. About 53 000 attendees came to our city to participate in this large scale event, which had speakers including António Costa, the Portuguese Prime Minister, Mike Schroepfer, Facebook's CTO, Werner Vogels, Amazon.com's CTO, Joseph Gordon-Levitt, Actor and HitRECORD Founder, among many others.

The Web Summit was divided into three pavilions and one center stage, having a total of 21 different conferences according to different themes. The 2<sup>nd</sup> Patient Innovation Awards Ceremony was held at the HealthConf on November 10<sup>th</sup> 2016. The room was full, as hundreds of people came to attend the ceremony.

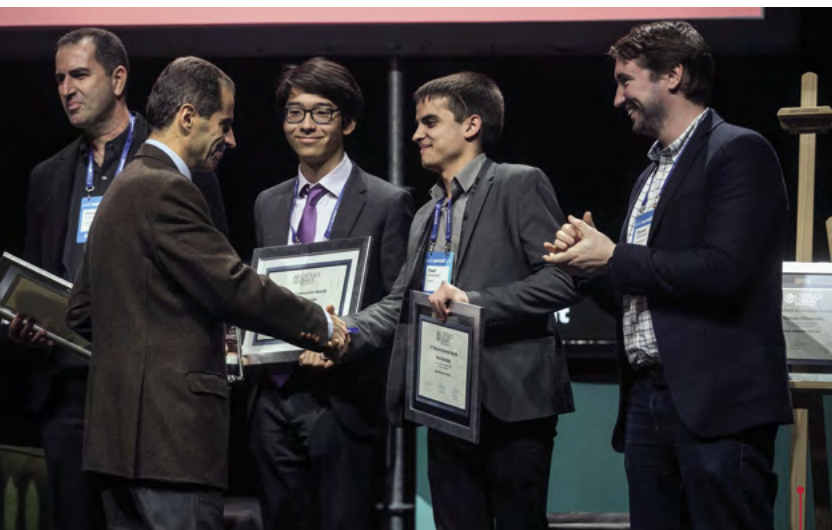


Pedro Oliveira held a brief presentation about the Patient Innovation Project, and then it was time to honor our laureates!

Professor Manuel Heitor, Portuguese Minister of Science, Technology and Higher Education, delivered the awards and diplomas to each laureate, and also gave a speech about the project and the importance of having people who innovate to overcome their own daily challenges.

Since Giesbert Nijhuis from the Netherlands, couldn't be present, Govert Jan Bijl de Vroe, the Dutch Ambassador in Portugal, received the award on his behalf.

After the ceremony, there was a panel moderated by Francisco Veloso, Dean of CATÓLICA-LISBON School of Business & Economics, about the importance of patients and caregivers in innovating and how to integrate these innovations into the healthcare system. Michael Seres talked about his experience as a patient, inventor and entrepreneur, and Joyce Lee explained the benefits of using design to improve the quality of life.



#### 10 PRESENTATION

Pedro Oliveira started the ceremony with a brief presentation.

#### 11 AWARDS CEREMONY

Professor Manuel Heitor, Portuguese Minister of Science, Technology and Higher Education, delivers the awards and diplomas to each laureate.



## 2016 LISBON WEB SUMMIT QUICK FACTS

**4**  
DAYS

**21**  
CONFERENCES

**53 000**  
ATTENDEES

12



13

### 12 AWARDS CEREMONY

Professor Manuel Heitor holds a speech after delivering the 2<sup>nd</sup> Patient Innovation Awards.

### 13 DEBATE

Moderated by Francisco Veloso, the debate was about the integration of patients innovations into healthcare system.

## 2 / Patient Innovation Awards

The 2<sup>nd</sup> Patient Innovation Awards @ Web Summit

# ...And the Patient Innovation Award goes to...



**Michael Seres (UK)**  
OSTOM-I™

Michael Seres was diagnosed with Crohn's disease when he was 12 years old. After over 20 operations and intestinal failure, he underwent a small bowel transplant at Churchill Hospital, Oxford, England, and started to use an ostomy bag. His own experience as an ostomy patient led him to design the initial Ostom-i Alert prototype whilst recovering from transplant. Ostom-i Alert allows patients to know when their ostomy bags are full so they can empty them without risking overflow. Ostom-i Alert addresses a very relevant need for patients who undergo intestinal procedures that require them to wear colostomy bags, often for the rest of their lives.

IN CATEGORY: PATIENT



**Giesbert Nijhuis (Netherlands)**  
LAESIECUSHION • HOW TO TAKE PHOTOS WITHOUT  
USING HANDS • BED COMPUTER

Giesbert had an accident that left him paralyzed from the neck down. He created his own website, LaesieWorks, where he shares ideas and solutions he developed so that he can live better with his condition. He will be awarded for all three of the following solutions: LaesieCushions, cushions to prevent pressure wounds for wheelchair users, hands free photo, a method for people who can't use their hands to take photos more independently, and the bed computer, an adaptation Giesbert made so he can work on his computer while lying down in bed.

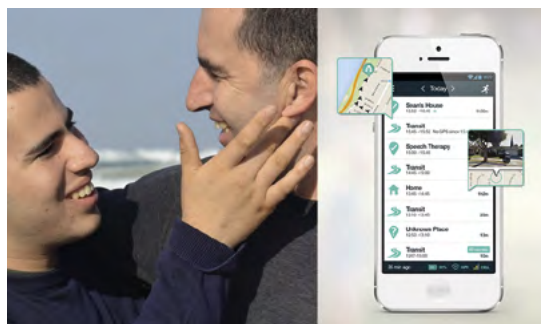
IN CATEGORY: SERIAL PATIENT INNOVATOR



**David Day (UK)**  
COMPUTER GAMES TO HELP WITH CYSTIC FIBROSIS

David Day, Alicia's father, developed these games with his colleagues to ease his daughter's suffering during Cystic Fibrosis treatments, while she did respiratory exercises. The games are played using a device which connects breathing tubes to the computer. Through this, children can control characters and shapes on the screen by exhaling at a certain pressure.

IN CATEGORY: CAREGIVER



**Doron Somer (Israel)**

ANGELSENSE

Doron Somer created AngelSense, in 2013, a GPS and voice monitoring technological solution designed for children with special needs such as Autism and Aspergers, such as the case of his son. After his 17-year-old autistic son suffered another mistreatment at the hands of a caregiver, Doron Somer sought to find a solution to help monitor Itamar's safety and well-being. AngelSense has advanced data analytics optimized for personal tracking, adaptive remote device control algorithms and its design meets the specific requirements of children with special needs and their families.

IN CATEGORY: CAREGIVER



**Pavel Kurbatsky (Russia)**

WALKING TALKING STICK

Pavel Kurbatsky was passionate about technology and electronics since he was a young boy. Inspired by blind people he met during time spent volunteering, he created a special walking stick and talking dark glasses. The stick has sensors at three levels: head, waist and feet, which scan the surroundings, and as soon as the user is about to approach an obstacle, he/she is alerted through a voice message, seeing as there are ear phones fitted into the glasses, so that they can avoid the obstacle. A GPS system is also fitted, which allows it to gather information about a particular location for future reference.

IN CATEGORY: COLLABORATOR



**Kenneth Shinozuka (USA)**

SAFEWANDER™

Kenneth's grandfather suffers from Alzheimer's disease. He often wanders alone at night. Since a very young age, Shinozuka has designed smart devices for his grandfather. Kenneth came up with a way to keep him safe - and help his aunt who looks after him: a device that is attached to clothing, designed to send an alert to a caregiver if a patient gets out of bed, and is connected to a smartphone app - SafeWander™.

IN CATEGORY: CAREGIVER



**Duncan Fitzsimons (UK)**

MORPH™ WHEELS

Duncan invented foldable wheels when he was a graduate student at the Royal College of Arts in London, for his bicycle. He then started getting emails from the wheelchair community telling him that this concept would be invaluable to wheelchair users, so he redesigned it as a wheelchair wheel. The MorphWheels™ allows users to fold their wheelchair up into a much smaller, neater package, so it can fit into the overhead locker of an airplane, or the trunk of a car.

IN CATEGORY: COLLABORATOR

# *The Patient Innovation Awards Forum*



14

## **PATIENT INNOVATION AWARDS FORUM**

*The Patient Innovation Awards Forum, hosted at CATÓLICA-LISBON School of Business & Economics, on November 9<sup>th</sup> 2016*

## The Patient Innovation (PI) team hosted the Patient Innovation Awards Forum at CATÓLICA-LISBON School of Business & Economics, on November 9<sup>th</sup> 2016

This was a pre Web Summit event open to the entire community, with several distinguished guests, as well as the 2<sup>nd</sup> PI Awards laureates. This way, our laureates had the chance to meet the Patient Innovation community and to introduce themselves as well as their innovations.

The Patient Innovation Awards Forum panel was composed of Francisco Veloso, former Dean of CATÓLICA-LISBON School of Business & Economics, who did the opening remarks, Pedro Oliveira and Helena Canhão, Patient Innovation Project Leaders, and Joyce Lee, MD, professor of University of Michigan and expert on Design Thinking in HealthCare.



We were also very humbled and honored to have the presence of Tzipora Rimon, the Israeli Ambassador in Portugal, as well as representatives from the UK and Russian Embassies in Portugal.

15

### **TZIPORA RIMON**

*Tzipora Rimon, the Israeli Ambassador in Portugal was the Israeli representative at the Patient Innovation Awards Forum.*

16

### **PATIENT INNOVATION AWARDS FORUM KEYNOTE SPEAKERS**

*Doron Somer, David Day, Joyce Lee (doctor and professor), Kenneth Shinozuka, Michael Seres and Pavel Kurbatsky (from left to right) brought their innovations and showed them, explaining what drove them to develop their new product.*





# Giving a hand

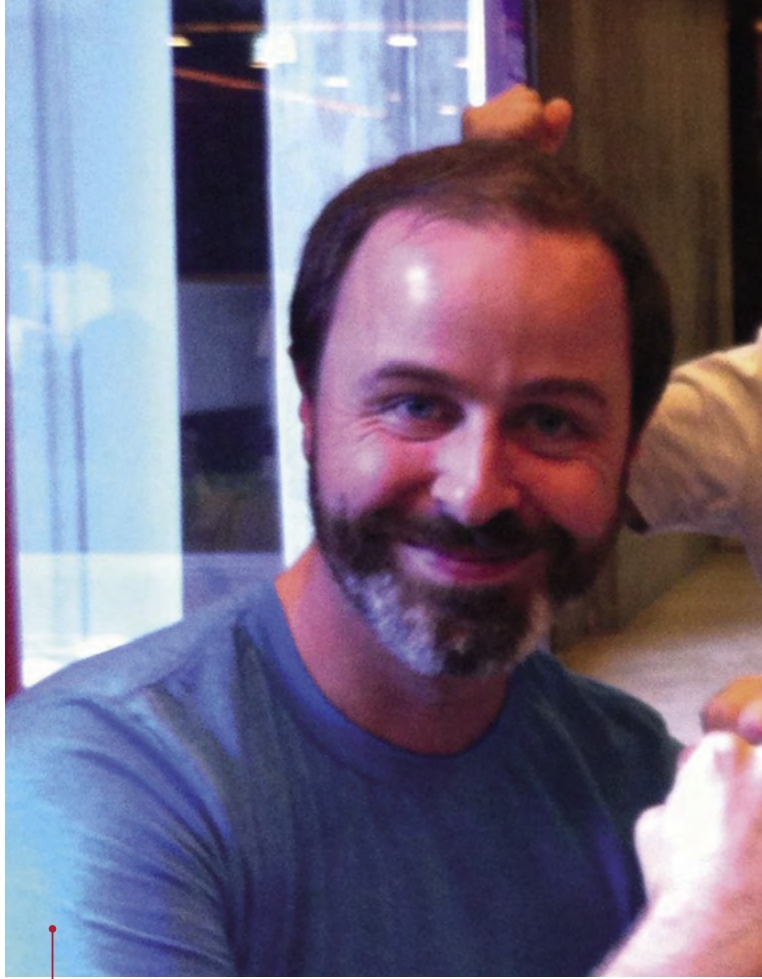


*“This platform has enormous potential to improve the lives of rare diseases sufferers. Patients and caregivers are innovators in their own right.”*

— **Katherine J. Strandburg**

PROFESSOR, NEW YORK UNIVERSITY SCHOOL OF LAW  
PATIENT INNOVATION ADVISORY MEMBER

# Giving a hand



17

One of the goals of Patient Innovation is to help patients, caregivers and collaborators develop and implement their own solutions. On July 13<sup>th</sup> 2015, the Patient Innovation team, with the help of Ivan Owen, gave a 3D printed hand and arm to a 7-year-old Portuguese boy, Nuno.

Nuno, who is also our youngest fellow on the team, also contributed by sewing some pieces of his new red and white gadget.

## 17 IVAN, NUNO AND SALOMÉ

*Ivan Owen, artist and 3D printing expert from ENABLE, Nuno, the Portuguese 7-year-old boy who received a 3D printed hand and arm, and Salomé Azevedo, from Patient Innovation team.*

## 18 NUNO

*Nuno trying out his new gadget.*



18





# 4 Activities



*“The Patient Innovation platform is a project with potentially great social value.”*

— Eric von Hippel

PROFESSOR, MIT SLOAN SCHOOL OF MANAGEMENT  
PATIENT INNOVATION ADVISORY MEMBER

# Health Innovation Challenge

The Health Acceleration Challenge was a “scale up” competition that focused on compelling, already-implemented health care solutions and helping them to grow and increase their impact through powerful networking and funding opportunities.

Patient Innovation participated in the Harvard Health Innovation Challenge on November 15<sup>th</sup> 2014. The project was selected as one of the 18 semi-finalists from 478 applications (from institutions such as Stanford University, Cleveland Clinic, Mayo Clinic, Kaiser Permanente, MD Anderson, Intermountain, Massachusetts General Hospital, and many more).

Patient Innovation was the only non-US project among all semi-finalists. Patient Innovation was also the most viewed (over 25 600 visualizations), most applauded and most commented on project in the competition.

Even though Patient Innovation did not win (others were considered to have a higher impact on the US health care system), we were very happy with the overall outcome and felt inspired by the overwhelming support given by our followers.

**Patient Innovation was the only non-US project among all the semi-finalists.**  
**Patient Innovation was the most viewed (over 25 600 visualizations), most applauded and most commented on project in the competition**



**+25 600**  
VIEWS



**364**  
APPLAUSES



**126**  
COMMENTS

# Patient Innovation recognized at summit with UN Secretary-General Ban Ki-moon



Patient Innovation was featured on the United Nations (UN) on November 30<sup>th</sup> 2016 in New York at the "Summit on Science and Technology Enablement for the Sustainable Development Goals", as an example of "Commitments to Collective Action".

We were one of the five projects selected as a case already contributing to two of the UN's sustainable development goals: Good health and Well-Being & Industry, Innovation and Infrastructure.

## 20 PEDRO OLIVEIRA AND ELLIS RUBINSTEIN

*Pedro Oliveira and Ellis Rubinstein, president and CEO of the New York Academy of Sciences.*



19

**BAN KI-MOON**  
*Former Secretary-General of the United Nations.*



20



# *arthritis*

noun ar·thri·tis \är-'thrī-təs\

*medical : a disease that causes  
the joints of the body to become  
swollen and painful*



21

**HELENA, ELSA AND ANA**

*Helena Canhão, MD, Patient Innovation project leader, Elsa Frazão Mateus and Ana Ribeiro, from Portuguese League Against Rheumatic Diseases (PLARD).*

# World Arthritis Day

**Patient Innovation has been developing some interesting activities with its partners Portuguese League Against Rheumatic Diseases (PLARD)**

The first activity was the Patient Innovation Challenge Day. This was a contest developed by PI and PLARD, launched on September 12<sup>th</sup> 2015, to celebrate World Arthritis Day on October 12<sup>th</sup>.

The contest's purpose was to stimulate platform members (as well as gain new ones) to identify and share innovative solutions, developed by patients and caregivers, who suffer from any kind of rheumatic disease, and by doing so, help them to improve their lives. Lisa Crites and Joaquina Teixeira, PI Award winners, made a video to help promote the challenge; Nuno, the 7-year-old little boy who got a 3D printed hand

and arm from PI and Ivan Owen, also contributed with a video.

After receiving several candidates, the PI team and PLARD selected two winners: Louis Plante, from Canada, and Carina Antunes, from Portugal. They each got an Amazon Gift Card as their prize. The winners were selected by the number of votes (likes on Facebook, the Patient Innovation platform and also on Twitter), and all of the solutions were evaluated by the Patient Innovation team and PLARD.

Patient Innovation also participated in the XVIII "Fórum de Apoio ao Doente Reumático", an event hosted by our partners PLARD in Lisbon on October 30<sup>th</sup> and 31<sup>st</sup> 2015, where the Patient Innovation team interacted with patients and Pedro Oliveira introduced the Patient Innovation project.

# SOS Refugees by Patient Innovation

In October 2015, Patient Innovation went to Macedonia to help refugees. SOS Refugees by Patient Innovation was an initiative that took Pedro Oliveira and Leid Zejnilovic to Tabanovce, on the border between Macedonia and Serbia, from the Greek border, where they bought hot meals, clothing and shoes for the refugees

Patient Innovation created a crowdfunding campaign, via PPL, a portuguese crowdfunding platform, with the purpose of raising 3 000€ to buy provisions in Tabanovce. By the end of the campaign - October 27<sup>th</sup> - 6 823€ were raised.

Thanks to the generosity of the campaign supporters, the SOS refugees initiative was able to offer food, beverages, winter clothes and shoes, including: 2 400 hot soup meals (that were served at the arrival of four different trains), 6 000 juices, 3 000 pieces of chicken pâté, 3 000 pieces of bread, 2 000 croissants, about 1 500 bananas, 125 pairs of shoes (mostly to children and young adults), about 1 200 pairs of socks, about 150 gloves, 150 scarves and 150 winter hats. In addition to the distribution of the goods, among other achievements, Patient Innovation helped a 105-year-old

blind refugee (who was traveling with her 67-year-old son) to reach the Serbian border.

All the collected funds reverted directly to the refugees - travel, accommodation, and the crowdfunding campaign were covered by the promoters of this initiative.

---

## 6 823€

RAISED FROM THE PATIENT INNOVATION CROWDFUNDING

22





23

In addition to the distribution of the goods, among other achievements, Patient Innovation helped a 105-year-old blind refugee to reach the Serbian border

## 22 FOOD AND CLOTHES

Food and clothing bought by the SOS Refugees initiative.

## 23 SOS REFUGEES CAMPAIGN LOGO

SOS Refugees gathered 6 823€ via crowdfunding.

## 24 SOS REFUGEES STATION

2 400 hot soup meals (that were served at the arrival of four different trains), 6 000 juices, 3 000 pieces of chicken pâté, 3 000 pieces of bread, 2 000 croissants, and about 1 500 bananas.

24



#### 4 / Activities

*Celebrating our 2<sup>nd</sup> year anniversary*

Patient Innovation was one of 11 innovations, from all over the world, distinguished by the office of the Prime Minister of the United Arab Emirates (UAE) that was featured at the 4<sup>th</sup> World Government Summit in Dubai on February 8<sup>th</sup> – 10<sup>th</sup> 2016.

The World Government Summit is a global event that promotes the exchange of knowledge in areas such as: government, technology and innovation.

The event brought together more than 4 000 world leaders, from over 90 countries. The speakers at the event included the former President of the United States, Barack Obama, the President of the World Bank Group, Jim Yong Kim, the Secretary-General of the OECD, José Ángel Gurría, the Prime Minister of Egypt, Sherif Ismail, the former President of Ireland, Mary Robinson, the former President of Mexico, Felipe Calderon, the former Prime Minister of France, Dominique De Villepin, among many other reputable individuals.

**Patient Innovation was one of 11 innovations, from all over the world, distinguished by the office of the Prime Minister of the United Arab Emirates (UAE)**

# *Celebrating our 2<sup>nd</sup> year anniversary*



25

عندما يسعى الفرد لمعالجة نفسه  
فإنه يساهم في علاج الآخرين.  
When patients set to help themselves  
and end up helping many others.



26

Patient innovation had a very prominent presence at the Summit, where a number of solutions were on display during the event:

- **3D printed hand**, (low cost 3D printing prosthetic hand and arm), a collaboration between Ivan Owen (USA) and the Patient Innovation team;

- **The Upsee™** (mobility device for children with motor impairment to allow the user to stand and walk), by Debby Elnatan (caregiver from Israel);

- **The Shower Shirt™**, (post-surgical, water-resistant garment designed to prevent post-surgical mastectomy drain sites, dialysis catheters and medical-ports from coming into contact with water while showering), by Lisa Crites (patient from USA) who also attended the event;

- **The Frequencer™**, (Low frequency generator for bronchial drainage), by Louis Plante (patient from Canada);

- **Feelipa**, (a code system developed so that blind and visually impaired people can see colors), by Filipa Nogueira Pires (caregiver from Portugal);

- **Billow Pillow**, (a pillow to help patients who had mastectomies sleep and rest better), by Marnie Rustemeyer (patient from USA) who also attended the event;

- **Removable thermal pockets**, (portable pockets that heat its user's hands), by students from JUNITEC (Portugal);

- **Exovasc®**, (aortic support device for patients who suffer from Marfan's Syndrome), by Tal Goleworthy (patient from UK).

## 25 ENTRANCE WGS 2016

World Government Summit in Dubai on February 8<sup>th</sup> 2016.

## 26 PATIENT INNOVATION STAND

Some of the innovations from Patient Innovation at the World Government Summit - Feelipa, Billow Pillow, Upsee.

PATIENT INNOVATION WINS

# *"Non-Profit Startup of The Year 2016" in London*

Patient Innovation  
won **The HealthCare  
Startup Awards  
2016** and was named  
Non-Profit Startup  
of The Year

The ceremony, promoted  
by HealthCare Society in  
London, was held on December  
17<sup>th</sup> 2016. Over 1000 startups were  
considered and 50 were shortlisted  
as finalists.

Patient Innovation



NON-PROFIT STARTUP  
OF THE YEAR

— 2016 —



# *AACSB distinguished Patient Innovation as Entrepreneurship Spotlight Challenge Honoree (2017)*

27 AACSB ENTREPRENEURSHIP  
SPOTLIGHT CHALLENGE 2017 AWARD

27

CATÓLICA-LISBON was one of four European business schools recognized by AACSB as Entrepreneurship Spotlight Challenge Honoree specifically for the work of Patient Innovation! AACSB is the world's largest business education alliance and includes 1,500 member organizations and more than 785 accredited business schools worldwide.

The Entrepreneurship Spotlight Challenge recognized 20 schools worldwide for their entrepreneurship programs and this recognition demonstrates CATÓLICA-LISBON leadership in creating and incubating cutting-edge innovative projects.





# *Beyond the Lab exhibition*

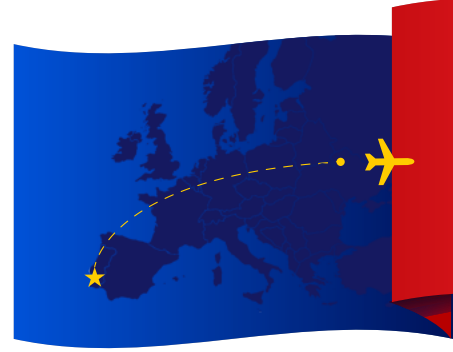


“  
*You have been hitting the target pretty well. It’s been an awesome time. I have been following you, and it’s amazing all the knowledge you were able to brought together. This project is very close to my heart, and to see you guys working so hard... It just amazes me. Thank you.*”

— **Louis Plante**

CREATOR OF THE FREQUENCER™  
1<sup>st</sup> PATIENT INNOVATION AWARD WINNER

# Beyond the Lab exhibition



*The exhibition will be moving around 29 european countries. Its opening was on July 6<sup>th</sup> 2016, in Bonn, and on July 7<sup>th</sup> 2016 at the Science Museum in London*

**PATIENT INNOVATION** – “THE PATIENTS TURNED MEDICAL INNOVATORS”  
AT THE SCIENCE MUSEUM

Patient Innovation was invited by the Science Museum of London to participate in an exhibition called “Beyond the Lab: The DIY Science Revolution”.

This exhibition explores the increasing number of inventions and scientific discoveries that are being made by hackers, patient groups and ordinary citizens – rather than by professional scientists and researchers.

The Patient Innovation team selected seven innovations, that are featured on the Patient Innovation platform, to be displayed at the exhibition:

- **ExoVasc®**, an aortic support created by Tal Golesworthy (one of the 1<sup>st</sup> PI Awards winners);

- **The Shower Shirt™**, a shirt that allows patients to protect surgical drains from water while showering, invented by Lisa Crites (one of the 1<sup>st</sup> PI Awards winners);

- **3D printing hand and arm**, low cost 3D printing prosthetic hand and arm, a collaboration of Ivan Owen (one of the 1<sup>st</sup> PI Awards winners) with the Patient Innovation team;

- **Upsee™**, mobility device for children with motor impairment to allow the user to stand and walk, developed by Debby Elnatan (one of the 1<sup>st</sup> PI Awards winners);

- **Ostom-i alert**, a sensor that alerts ostomized patients on how full their ostomy bags are, developed by Michael Seres (one of the 2<sup>nd</sup> PI Awards winners);

- **Removable thermal pockets**, portable pockets that heat its user’s hands, created by students from JUNITEC, from Instituto Superior Técnico, Portugal;

- **ViEx**, a wooden device to help exercise both hands using strings, invented by Sarah Betts from USA.



*The exhibition opening  
was on July 6<sup>th</sup> in Bonn,  
and on July 7<sup>th</sup> 2016 at  
the Science Museum in  
London, and it will be  
moving around  
**29 European countries***



# Patient Innovation EUROPEAN TOUR

AS PART OF THE EXHIBITION

## BEYOND THE LAB: THE DIY SCIENCE REVOLUTION

2016 Jul-Aug	BONN, GERMANY	2017 Apr-May	PALLINI, GREECE
2016 Jul-Aug	LONDON, UK	2017 Jul-Aug	MECHELEN, BELGIUM
2016 Jul-Sep	WARSAW, POLAND	2017 Jul-Aug	CESIS, LATVIA
2016 Jul-Aug	LJUBLJANA, SLOVENIA	2017 Jul-Aug	BUDAPEST, HUNGARY
2016 Sep-Nov	LUXEMBOURG, LUXEMBOURG	2017 Jul-Aug	KALKARA, MALTA
2016 Sep-Nov	LOŠINJ, CROATIA	2017 Oct-Nov	KERKRADE, NETHERLANDS
2016 Oct-Dec	GRANADA, SPAIN	2017 Oct-Nov	VILNIUS, LITHUANIA
2016 Oct-Dec	COPENHAGEN, DENMARK	2017 Oct-Nov	PARDUBICE, CZECH REPUBLIC
2017 Jan-Mar	LISBON, PORTUGAL	2017 Oct-Nov	SOFIA, BULGARIA
2017 Jan-Mar	NICOSIA, CYPRUS	2018 Jan-Feb	DUBLIN, IRELAND
2017 Jan-Mar	BRATISLAVA, SLOVAKIA	2018 Jan-Feb	VANTAA, FINLAND
2017 Jan-Mar	NORRKÖPING, SWEDEN	2018 Jan-Feb	TRENTO, ITALY
2017 Apr-Jun	TARTU, ESTONIA	2018 Jan-Feb	CLUJ-NAPOCA, ROMANIA
2017 Apr-May	BORDEAUX, FRANCE	2018 Apr-May	LUGANO, SWITZERLAND
2017 Apr-May	LINZ, AUSTRIA		





# Patient Innovation Research



*“Doctors make the worst patients. Maybe in the future patients will make the best doctors”*

— **Carlos Moedas**

EUROPEAN COMMISSIONER FOR RESEARCH, SCIENCE AND INNOVATION  
IN 1<sup>st</sup> PATIENT INNOVATION AWARDS CEREMONY, LISBON, 2015

# Research and Outreach

We started as a research project and, ever since, research is at the core of our existence. We are privileged to experience wonderful collaborations with many patients and patients' associations worldwide.

In our work, we focus on applied research, gathering evidence about innovation activity by patients and caregivers.

And it has been extremely productive. Seven scientific journal papers/book chapters and hundreds of conference presentations were all invaluable experiences for us. We have learned a lot about patient innovation, and we have spread the Patient Innovation word about our role models, ordinary people with extraordinary contribution to medical care.

We were lucky to have seven wonderful students from Católica-Lisbon School of Business & Economics do their Master thesis on the topics of Patient Innovation. Matilde Czernin, Tomás Fidelis, Rita Oliveira, Viktoria Shcherbatiuk, Joana Roldão, Jan-Philipp Dreier and João Pedro Silva, besides the praise from their committees, they all obtained high grades for their contributions. Moreover, within the Carnegie Mellon Portugal program, our colleague, Leid Zejnilovic, completed his doctoral thesis in 2014 with Magna cum Laude, and two thirds of the thesis focused on Patient Innovation. The degree is jointly offered by Carnegie Mellon University, CATÓLICA-LISBON School of Business & Economics and Instituto Superior Técnico.

Also, within the Carnegie Mellon Portugal program, our colleague, Leid Zejnilovic, completed his doctoral thesis in 2014 with Magna cum Laude, and two thirds of the thesis focused Patient Innovation



*“Our research shows that patients and their caregivers are able to create many different types of innovations. Some actually improve the patient’s health or alleviate symptoms; others make daily life easier.”*

**Helena Canhão, Pedro Oliveira, Leid Zejnilovic**

**NEJM Catalyst**

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Care Redesign Leadership New Marketplace Patient Engagement

**Patient Engagement**

**Patient Innovation — Empowering Patients, Sharing Solutions, Improving Lives**

Helena Canhão, MD, PhD, Pedro Oliveira, PhD & Leid Zejnilovic, PhD  
Universidade Nova, Lisbon  
Universidade Católica Portuguesa, Lisbon

*“We found that patients and caregivers have significant innovative capabilities and have developed various solutions, treatments, and medical aid devices for themselves (e.g. about 50% of the solutions for cystic fibrosis were developed by the patients).”*

**Helena Canhão, Pedro Oliveira, Leid Zejnilovic**

**REVOLUTIONISING HEALTHCARE BY EMPOWERING PATIENTS TO INNOVATE**

**\*Helena Canhão,<sup>1</sup> Leid Zejnilovic,<sup>2</sup> Pedro Oliveira<sup>2</sup>**

<sup>1</sup> CEDOC, School of Medicine, NOVA University of Lisbon, Lisbon, Portugal  
<sup>2</sup> Católica-Lisbon School of Business and Economics, Catholic University of Portugal, Lisbon, Portugal  
\*Correspondence to: [helenacanhao@gmail.com](mailto:helenacanhao@gmail.com)

**Disclosure:** The authors have declared no conflicts of interest.  
**Received:** 07/03/16 **Accepted:** 04/04/16  
**Citation:** EMJ Innov. 2017;[1]:31-34.

**INTRODUCING A NEW PARADIGM OF HEALTHCARE INNOVATION**

or health condition. We found that patients and caregivers have significant innovative capabilities and have developed various solutions, treatments,

*“Given that hundreds of millions of people worldwide are afflicted by rare diseases, patient and their caregivers can be a tremendous source of innovation for many who are similarly afflicted. Our findings suggest that many patients could be greatly assisted by improved diffusion of known solutions and best practices to and among patients and their caregivers.”*

**Pedro Oliveira, Leid Zejnilovic, Helena Canhão, Eric von Hippel**

Oliveira et al. *Orphanet Journal of Rare Diseases* (2015) 10:41  
DOI 10.1186/s13023-015-0237-2

**ORJRD** ORPHANET JOURNAL OF RARE DISEASES

**RESEARCH**

**Open Access**

## Innovation by patients with rare diseases and chronic needs

Pedro Oliveira<sup>1\*</sup>, Leid Zejnilovic<sup>1,2</sup>, Helena Canhão<sup>3</sup> and Eric von Hippel<sup>4</sup>

**Abstract:** We provide the first empirical exploration of disease-related innovation by patients and their caregivers. Our aims were to explore to what degree do patients develop innovative solutions; how many of these are unique developments; and do these solutions have positive perceived impact on the patients' overall quality of life? In addition, we explored the factors associated with patient innovation development, and sharing of the solutions that the patients developed.

**Methods:** We administered a questionnaire via telephone interviewing to a sample of 500 rare disease patients and caregivers. The solutions reported were pre-screened by the authors for their fit with the self-developed innovation aim of the study. All the reported solutions were then validated for their novelty by two medical professionals. Logistic regression models were used to test the relationships between our key variables, patient innovation and solution sharing.

# What we learned so far

The most important thing we have learned so far is that there are many people who actively try to manage their problems resulting from health disorders and develop solutions. We are inspired by their stories of creativity, strength in facing adversity, their altruism, and positive energy that overcomes the challenges they face.

As we learn about patient innovation, we share our insights in academic publications. So far, we have written seven scientific journal papers/book chapters and we have several new projects underway.

In a paper published in "Orphanet Journal of Rare Diseases" (2015), we reported the results of an exploratory study of innovative activity among individuals afflicted with rare diseases. From 500 phone-surveyed individuals, 53% reported taking initiative to deal with a health related issue. About 8% of the interviewees had developed solutions that introduced some level of novelty. Only 5% of the authors with novel solutions have shared information about their solution with medical professionals. These findings emphasize the need to carefully design public health policies that would empower patients and caregivers to safely develop and share their solutions.

Let us use this opportunity to thank the association of people with rare and mental diseases, *Raríssimas*, specifically director, Paula Brito e Costa, for their professionalism and support for our project.

We are convinced that good times are ahead. Not only that technology enables many individuals to turn their ideas into realities, but also digital platforms are mushrooming, covering various needs of those with an interest in health care. We shared some of our thoughts about the opportunities that arise from this trend in a book chapter in *Boundaryless Hospital, "Rethink and Redefine Health Care Management"* (2016).

## only 5%

**of the authors with novel solutions have shared information about their solution with medical professionals**

Also, we were honored by an invitation to contribute with a chapter on Patient Innovation in the book written by the community of open and user innovation scholars, entitled "Revolutionizing Innovation: Users, Communities, and Open Innovation" (2016).

Novel solutions developed by patients and caregivers are sometimes just a result of a serendipitous insight. But, more often, the developers carry out research, collect complementary skills, resources, and complete many attempts of trial and error before a usable solution comes to light.



## THE VAST POTENTIAL OF PATIENT INNOVATION

- New innovation for patient = 28%
- New innovation for the world = 8%
- Did not innovate = 64%

“Patient Innovation: When patients set to help themselves and end up helping many others”. The book features personal stories of the Patient Innovation platform users, the patients, caregivers, and collaborators who created innovative solutions to cope with a health disorder. We are never indifferent

**Humbled by all the wonderful experiences of sharing the Patient Innovation stories, we decided also to share them in a book**

Using this process model, we discuss the challenges and potential to support the innovation process by patients, and how platforms - such as Patient Innovation – can help making better use of patient innovations. The book, “Governing Medical Research Commons”, is a part of Cambridge Series on Governing Knowledge Commons, and was printed in 2016.

Humbled by all the wonderful experiences of sharing the Patient Innovation story, we decided also to share them in a book called:

We made a simple process model of patient innovation, to guide our thoughts about future actions and shared it in a book chapter entitled “Challenges and opportunities in developing and sharing solutions by patients and caregivers, the story of a knowledge commons for patient innovation”.

when hearing or reading about these stories, and we hope that our readers will feel the same.

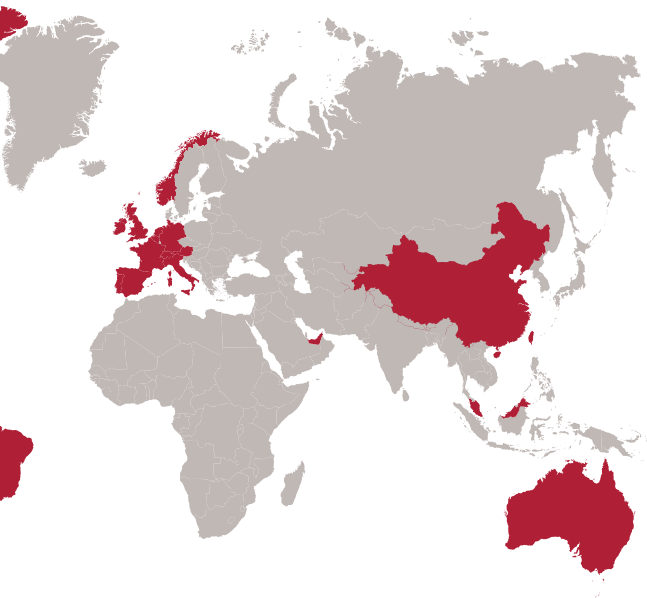
The book is planned to be released for publication in 2018.

In 2014, the Portuguese Society for Rheumatology included questions about patient innovation activity in a national longitudinal study of rheumatology and health among residents in Portugal. We asked questions about the development, adoption, and the attitudes towards patient innovation. We are excited to share our new discoveries from this research endeavour, soon.



# Conference Presentations

- 1 **Advisory Board Meeting at MIT**  
Boston, USA, 2014
- 2 **Patient Innovation Launch Event at CATÓLICA-LISBON**  
Lisbon, Portugal, 2014
- 3 **Technoport**  
Trondheim, Norway, 2014
- 4 **Crowdsourcing Week Global**  
Singapore, 2014
- 5 **MIT Innovation Lab Meeting**  
Boston, USA, 2014
- 6 **European Conference on Rare Diseases & Orphan Products**  
Berlin, Germany, 2014
- 7 **Patient Innovation in the management of Multiple Sclerosis at SPEM - Portuguese Multiple Sclerosis Society**  
Lisbon, Portugal, 2014
- 8 **10<sup>th</sup> anniversary of Tal Golesworthy External Aortic Support**  
London, UK, 2014
- 9 **Medical User Innovation Medical Commons Conference**  
New York, USA, 2014
- 10 **Rethink and Redefine Health Care Management at Boundaryless Hospital**  
Leipzig, Germany, 2014
- 11 **European Science Foundation at CUBE - CATÓLICA-LISBON Research Unit**  
Lisbon, Portugal, 2014
- 12 **12<sup>th</sup> Open and User Innovation Conference at Harvard Business School**  
Boston, USA, 2014
- 13 **Academy of Management Meeting**  
Philadelphia, USA, 2014
- 14 **Shape Europe from Ideas to Action: Entrepreneurship and Innovation in Europe at Global Shapers Community**  
Lisbon, Portugal, 2014
- 15 **MBA Alumni Association**  
Lisbon, Portugal, 2014
- 16 **Innovation Days 2014 at Maison Internationale de la Cité Universitaire**  
Paris, France, 2014
- 17 **Aging and Rheumatic Diseases Forum at Portuguese League Against Rheumatic Diseases**  
Lisbon, Portugal, 2014
- 18 **Medical Informatics at University of Porto**  
Porto, Portugal, 2014
- 19 **Patient Innovation Care at Faculdade de Ciências da Saúde, Universidade da Beira Interior**  
Covilhã, Portugal, 2015
- 20 **Católica-Porto Research Seminar**  
Porto, Portugal, 2015
- 21 **Advisory Board meeting at MIT**  
Boston, USA, 2015
- 22 **International Health Management at Imperial College Business School London**  
London, UK, 2015



- 23 **Roadshow: Investment Plan for Europe at CATÓLICA-LISBON**  
Lisbon, Portugal, 2015
- 24 **XVI Congress of Portuguese Society of Physical Medicine and Rehabilitation**  
Lisbon, Portugal, 2015
- 25 **Innovation in the health sector at Innovation Forum at Hospital Israelita Albert Einstein**  
São Paulo, Brazil, 2015
- 26 **VI International Congress of the Child and Teenager at Universidade Lusíada de Lisboa**  
Lisbon, Portugal, 2015
- 27 **Forum on Healthcare Innovation at Harvard Business School**  
Boston, USA, 2015
- 28 **Patient Innovation: how patients, by helping themselves, end-up helping many others like them at School of Public Health**  
Lisbon, Portugal, 2015
- 29 **eHealth, mHealth and telemedicine at School of Public Health**  
Lisbon, Portugal, 2015
- 30 **Opening Up to an Era of Innovation: a New Start For Europe**  
Brussels, Belgium, 2015
- 31 **BIG Impact Award at SIWF'15 Social Innovation World Forum**  
Lisbon, Portugal, 2015
- 32 **22<sup>nd</sup> EurOMA Conference**  
Neuchâtel, Switzerland, 2015
- 33 **II Social Entrepreneurship Forum**  
Porto, Portugal, 2015
- 34 **Health Innovation and Operations Forum at CATÓLICA-LISBON**  
Lisbon, Portugal, 2015
- 35 **13<sup>th</sup> Open and User Innovation Society Meeting**  
Lisbon, Portugal, 2015
- 36 **1<sup>st</sup> Patient Innovation Awards**  
Lisbon, Portugal, 2015
- 37 **Academy of Management Meeting**  
Vancouver, Canada, 2015
- 38 **European Students' Conference at Charité – Universitätsmedizin Berlin**  
Berlin, Germany, 2015
- 39 **Expert Experience Exchange Program**  
Berlin, Germany, 2015
- 40 **Forum Social Economy – Organization and Cooperation**  
Évora, Portugal, 2015
- 41 **Patient Innovation and adoption: the role of the content of social interactions at Rotterdam School of Management**  
Rotterdam, Netherlands, 2015
- 42 **Jumping start Healthcare Innovation: Citizen engagement, Sharing Economy, Online Communities**  
Brussels, Belgium, 2015
- 43 **TEDx at TUM**  
Munich, Germany, 2015
- 44 **XVIII Forum of Support to the Rheumatic Patient**  
Lisbon, Portugal, 2015
- 45 **HSM Expomanagement**  
São Paulo, Brazil, 2015
- 46 **1<sup>st</sup> Iberic Symposium in Vertebro-Medullary lesions**  
Alcoitão, Portugal, 2015

## 6 / Patient Innovation Research

### Conference Presentations

- 47 **Advisory Board meeting at MIT**  
Boston, USA, 2016
- 48 **Politecnico di Milano**  
Milan, Italy, 2016
- 49 **World Government Summit 2016 – Edge of Government**  
Dubai, UAE, 2016
- 50 **Health Marathon at Champalimaud Foundation**  
Lisbon, Portugal, 2016
- 51 **CATÓLICA-LISBON Alumni based in Madrid at Spanish Portuguese Embassy**  
Madrid, Spain, 2016
- 52 **eHealth to better Health: engineering & tech will shape healthcare at Instituto Superior Técnico**  
Lisbon, Portugal, 2016
- 53 **Rare Disease Day at i3S**  
Porto, Portugal, 2016
- 54 **AIMS2016 – the Annual International Medical Students Meeting**  
Lisbon, Portugal, 2016
- 55 **ANDAR – Arthritis Day**  
Lisbon, Portugal, 2016
- 56 **Direct Digital Manufacturing for Medicine**  
Marinha Grande, Portugal, 2016
- 57 **My Future, my medicine**  
Lisbon, Portugal, 2016
- 58 **Hospital Fernando da Fonseca**  
Amadora, Portugal, 2016
- 59 **HOPE (European Hospital and Healthcare Federation) and the Value Creation in Healthcare**  
Lisbon, Portugal, 2016
- 60 **LOIS at Ludwig Boltzmann Gesellschaft GmbH**  
Vienna, Austria, 2016
- 61 **Building Global Entrepreneurs**  
Lisbon, Portugal, 2016
- 62 **China University Summer School Association –**  
Shanghai, China, 2016
- 63 **Beyond the Lab exhibition opening at London Science Museum**  
London, UK, 2016
- 64 **14<sup>th</sup> Open and User Innovation Society meeting at Harvard Business School**  
Boston, USA, 2016
- 65 **Festival Przemiany and Beyond the Lab exhibition at Centrum Nauki Kopernik**  
Warsaw, Poland, 2016
- 66 **Stanford Medicine X**  
Stanford, USA, 2016
- 67 **University of San Diego**  
San Diego, USA, 2016
- 68 **APDC 26 Digital Business Congress**  
Lisbon, Portugal, 2016
- 69 **European Researchers Night at Ciência Viva**  
Lisbon, Portugal, 2016
- 70 **Beyond the Lab exhibition opening at Tycho Brahe Planetarium**  
Copenhagen, Denmark, 2016
- 71 **EIT Health Design Thinking Competition**  
Erlanger, Germany, 2016
- 72 **IPPOSI - Patients Driving Health Innovation Conference**  
Dublin, Ireland, 2016
- 73 **Health 2.0 Meetup**  
Lisbon, Portugal, 2016
- 74 **ICF 2016 – International Annual Conference: Inspiring CreARTivity**  
Lisbon, Portugal, 2016
- 75 **Summit on Sustainable Development Goals at New York Academy of Sciences**  
New York, USA, 2016
- 76 **XIV Symposium of Portuguese Association of Urology**  
Lisbon, Portugal, 2016

- 77 **Patient Innovation Awards Forum at CATÓLICA-LISBON**  
Lisbon, Portugal, 2016
- 78 **2<sup>nd</sup> Patient Innovation Awards at Web Summit**  
Lisbon, Portugal, 2016
- 79 **Responsible Research and Innovation in action**  
Brussels, Belgium, 2016
- 80 **Leaping Forward**  
Lisbon, Portugal, 2016
- 81 **Portuguese Association for Hospital development**  
Lisbon, Portugal, 2016
- 82 **Leaping Forward**  
Porto, Portugal, 2016
- 83 **Oeiras International School**  
Oeiras, Portugal, 2017
- 84 **Beyond the Lab exhibition opening at Ciência Viva**  
Lisbon, Portugal, 2017
- 85 **Lisbon Living+**  
Lisbon, Portugal, 2017
- 86 **Being Rare at i3S**  
Porto, Portugal, 2017
- 87 **Women in Business**  
Lisbon, Portugal, 2017
- 88 **Bayer Innovation Day**  
Berlin, Germany, 2017
- 89 **Beyond the Lab exhibition panel**  
Alcanena, Portugal, 2017
- 90 **Leading the Heart**  
Lisbon, Portugal, 2017
- 91 **Portugal eHealth Summit**  
Lisbon, Portugal, 2017
- 92 **Responsible Research & Innovation in the Health Industry**  
Brussels, Belgium, 2017
- 93 **Social Innovation and Performance at Universidade de Trás os Montes e Alto Douro**  
Vila Real, Portugal, 2017
- 94 **TEDxFACTUNL**  
Lisbon, Portugal, 2017
- 95 **SUPERA/TOM Porto**  
Porto, Portugal, 2017
- 96 **European Parliament**  
Brussels, Belgium, 2017
- 97 **QUIS 2017**  
Porto, Portugal, 2017
- 98 **Carnegie Mellon Portugal Symposium 2017 at Porto Business School**  
Porto, Portugal, 2017
- 99 **From interns to interns**  
Faro, Portugal, 2017
- 100 **15<sup>th</sup> Open and User Innovation Society meeting**  
Innsbruck, Austria, 2017
- 101 **The Interdisciplinary Global Governance Symposium**  
Frascati, Italy, 2017
- 102 **Alcoitão Rehabilitation Center**  
Alcoitão, Portugal, 2017
- 103 **MIT Innovation Lab Meeting**  
Boston, USA, 2017
- 104 **Next Level**  
Lisbon, Portugal, 2017
- 105 **Association “Os Francisquinhos”**  
Lisbon, Portugal, 2017
- 106 **Cornell SC Johnson College of Business**  
New York, USA, 2017
- 107 **European Researchers Night at Ciência Viva**  
Lisbon, Portugal, 2017

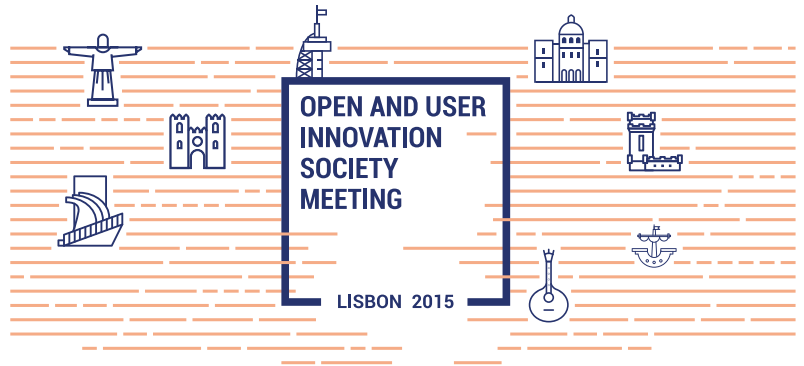
# *Open and User Innovation 2015*

The International Open and User Innovation Meeting (OUI) is the leading academic conference on Open and User Innovation and was hosted by CATÓLICA-LISBON School of Business & Economics, from July 13<sup>th</sup> to July 15<sup>th</sup> 2015



Calouste Gulbenkian Foundation was the venue chosen to bring together around 300 researchers from various disciplines (such as Innovation, Management, Health, Strategic Management, Organization, Design, Marketing, Entrepreneurship, and Public Policy) to exchange recent research findings and new plans related to Open and User Innovation. The Patient Innovation Awards ceremony was the event that opened the OUI. The possibility to host this event is the result of the strong investment of CATÓLICA-LISBON in the development of the area of innovation

and entrepreneurship, and specifically in the area of open and user innovation. This is also reflected in the growing group of faculty and researchers in this area that are now active in the school, the establishment of a dual PhD program with Carnegie Mellon University in Technological Change and Entrepreneurship, a faculty exchange with MIT Sloan School of Management in the context of the Lisbon MBA, as well as a wide range of educational and outreach activities designed to impact the community, such as Patient Innovation.



JULY 13<sup>TH</sup> - JULY 15<sup>TH</sup>  
[www.oui2015.clsbe.lisboa.ucp.pt](http://www.oui2015.clsbe.lisboa.ucp.pt)



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#### OUI2015

*The Open and User Innovation society meeting took place at Fundação Calouste Gulbenkian from July 13<sup>th</sup> to July 15<sup>th</sup> 2015.*



# *In the media*



*“This is a brilliant project that will significantly help patients across many diseases.”*

**— Paula Brito e Costa**

FOUNDER AND PRESIDENT OF RARISSIMAS — ASSOCIAÇÃO DE DOENÇAS RARAS

# We are all over the news!

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## HORIZON, THE EU RESEARCH AND INNOVATION MAGAZINE (BELGIUM)



*"Businessman Pedro Oliveira and medic Helena Canhão manage an interdisciplinary team that reviews innovative ideas by patients, making them accessible through the Patient Innovation website", 2017*

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## EL PAÍS BRASIL (BRASIL)



*"Oliveira and its colleagues created Patient Innovation in February 2014, and he says that they received more than 1200 independent submission proposals. A medical team studies all of them; about half of them is considered worthy of being live on the website", 2016*

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## SANITÀ 24 (ITALY)



*"«User innovation»: when the patient is promoting innovation in therapies", 2016*

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## BUSINESS DAILY AFRICA (KENYA)



*"New digital platform that allows patients to share health solutions", 2016*

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## WYBORCZA (POLSKA)



*"Patients share ideas for their illness", 2016*

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## NATIONAL GEOGRAPHIC POLSKA (POLSKA)



*"Pedro Oliveira and Helena Canhão are the creators of the Portuguese Patient Innovation portal, encouraging patients around the world to make their own solutions and medical inventions available. Thanks to Patient Innovation, amateur solutions and improvements have come to the widespread need, and some of them are already in widespread use in hospitals and medical facilities", 2016*

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## RDP INTERNACIONAL (PORTUGAL)



*"The Patient Innovation project has been reaching patients from around the world for two years now and helps them improve their lives", 2016*

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## RTP (PORTUGAL)



*"To share solutions that simply the life of who is sick and of who takes care of them. The idea resulted in a Portuguese digital platform, developed by CATÓLICA-LISBON, that reaches everyone in the world", 2015*

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## RTP (PORTUGAL)



*"It consists of an international, multilingual, and non profit platform that has the purpose of facilitating the sharing of innovative solutions developed by patients and caregivers of any disease", 2015*

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**RTP/MARATONA DA SAÚDE  
(PORTUGAL)**



**MARATONA  
da saúde**

*"This project, started in Portugal, has reached the five continents and has partnerships in 30 countries. So far it has shared 500 innovations, over 200 regarding neurodegenerative diseases, and was able to help countless patients through knowledge sharing", 2015*

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**RTP (PORTUGAL)**



*"The London Science Museum selected a single Portuguese Project, Patient Innovation, to be part of an European exhibition that aims to highlight the citizen's importance in research and scientific innovation", 2016*

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**ANTENA 2 (PORTUGAL)**



*"Patient Innovation is a platform that was born as a research project, in Católica Lisbon, cooperating with other institutions and universities such as MIT, Carnegie Mellon, among others, integrating academics and researchers in several areas (Health, Management, Engineering, Law)", 2016*

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**ANTENA 1 (PORTUGAL)**



*"Created in the last year, it promotes the global sharing of small solution to improve the well-being of several patients. The first Patient Innovation Awards were delivered just now, honoring several patients, caregivers, and international collaborators. A Portuguese caregiver was honored", 2015*

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**SIC NOTÍCIAS (PORTUGAL)**



*"CATÓLICA-LISBON has a platform featured among the 18 most innovative projects for Harvard Business School, among the 475 in contest from all over the world. It consists of a project in Healthcare, called Patient Innovation", 2014*

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**SIC (PORTUGAL)**



*"Medical and innovative solutions! Visit the website [www.patient-innovation.com](http://www.patient-innovation.com) and discover a platform that promote the sharing of knowledge between patients and caregivers", 2015*

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**↓ TVI (PORTUGAL)**



*"Patient Innovation: social network that allows the sharing of innovative solutions for rare diseases patients", 2014*

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**SIC NOTÍCIAS (PORTUGAL)**



*"On the World Health Day, Dr. Helena Canhão was in the morning show to talk about Patient Innovation, a two-year-old project that listens to patients and caregivers about solutions for several health problems", 2016*

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**SIC NOTÍCIAS (PORTUGAL)**



*"The biggest startups event has 600 keynote speakers from all over the world. Pedro Oliveira and Helena Canhão participate in a conference regarding Health", 2016*

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**SIC NOTÍCIAS (PORTUGAL)**



*"Beyond the Lab is an exhibition, open to the public, in Lisbon... That Future Today went visit. It shows cases of sciencs and non sciencs that with own means contribute to increase knowledge or even to improve lives", 2017*

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**TVI 24 (PORTUGAL)**



*"Portuguese platform shows the world simple ideas. This idea, shared all over the world, help the life of many people who deal with diseases", 2015*

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EXPRESSO (PORTUGAL)

## Expresso

*"Patient Innovation is an online platform where patients and caregivers can share the solutions they created or used to heal or deal with a disease that they couldn't solve in any other way, traditional or not", 2017*

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EXPRESSO (PORTUGAL)

## Expresso

*"But to make research centered on the patients is more than knowing about their pathologies. According to Helena Canhão, rheumatologist who co-leads Patient Innovation, it is also about giving voice to who participates in the process, either by sharing their needs, either by participations on the development process, testing and innovations improvement", 2017*

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EXPRESSO (PORTUGAL)

## Expresso

*"Nuno has eight years old and became news after he got a hand made by other skilled hands – who designed the model -, a genius simplifying gadget that was made in a 3D printed located in the online Patient Innovation platform headquarters, at CATÓLICA-LISBON", 2016*

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EXPRESSO (PORTUGAL)

## Expresso

*"A lot of people tried to prevent this platform from being successful. Fortunately we were able to launch the platform and in two years we collected over than 600 innovations, from a global community with over 37.000 diseases or caregivers", 2016*

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EXPRESSO (PORTUGAL)

## Expresso

*"Pedro Oliveira, professor at CATÓLICA-LISBON School of Business and Economics, leads an innovative project that help projects idealized by patients to come to life, in order to reduce their limitations", 2016*

---

EXPRESSO (PORTUGAL)

## Expresso

*"Pedro Oliveira had the idea of creating a social network where patients from all over the world could exchange their innovative solutions. That's how Patient Innovation was born", 2016*

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PÚBLICO (PORTUGAL)



*"The Patient Innovation digital platform aims to create an international global sharing in which patients, and not only, share with each other innovations to help with rare diseases treatments", 2017*

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PÚBLICO (PORTUGAL)



*"These five medical innovations were not made by doctors", 2016*

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PÚBLICO (PORTUGAL)



*"Social network for patients with rare diseases opens until the end of the year", 2013*

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DIÁRIO DE NOTÍCIAS (PORTUGAL)

## Diário de Notícias

*"It was the Summer of 2015, and Nuno doesn't remember what he said at the time, when he put on, for the first time, the plastic hand, almost right away from the 3D printer that Patient Innovation has in its office, at CATÓLICA-LISBON", 2017*

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JORNAL DE NOTÍCIAS (PORTUGAL)



*"Patient Innovation is an online platform used to share ideas that help in the daily lives of people who struggle with diseases. The ideas came from patients and caregivers", 2015*

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↓ OBSERVADOR (PORTUGAL)

## OBSERVADOR ●●

*"The Patient Innovation Awards distinguish patients and caregivers who create solution that can help people dealing with the same diseases. The seven winners were present at the Web Summit", 2016*

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**OBSERVADOR (PORTUGAL)**

**OBSERVADOR** ●●

*"The platform is based on a social network that connects patients with each other and allows the sharing of solutions and treatments. The best ideas of this platform will be recognized at the Web Summit", 2017*

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**OBSERVADOR (PORTUGAL)**

**OBSERVADOR** ●●

*"Patient Innovation is an initiative led by CATÓLICA-LISBON School of Business and Economics and stimulates patients, caregivers and collaborators to develop solutions that can help improve the quality of life of who deals with the same diseases or physical conditions", 2017*

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**EL PAÍS (SPAIN)**

**EL PAÍS**

*"Patient Innovation is a digital platform created by a group from CATÓLICA-LISBON School of Business and Economics. It allows patients who have developed solutions for their illnesses to share what they have learned or invented", 2016*

---

**EL INDEPENDIENTE DE GRANADA (SPAIN)**



*"Regarding patients who develop innovations to improve their quality of life, the Portuguese organization Patient Innovation shows solutions from a 3D printer to a pack for diabetics designed by a 10-year-old girl", 2016*

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**WORLD ECONOMIC FORUM (SWITZERLAND)**



*"Patient Innovation is a website set up by a group at the CATÓLICA-LISBON School of Business and Economics. It allows patients who've developed their own solutions for their illnesses to share what they've learned or invented. The project leader is Pedro Oliveira. His original interest was in user innovation generally: the part that people who use products and services can play in developing new strategies and procedures", 2016*

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**NEUE ZÜRCHER ZEITUNG (SWITZERLAND)**

**Neue Zürcher Zeitung**

*"With the aim of raising this still largely untapped idea, researchers from Portugal, Pedro Oliveira, from Catolica-Lisbon School of Business and Economics recently founded an Internet platform for patients (www.patient-innovation.com). Registered users have the opportunity to present self-developed strategies - chemistry and invasive procedures are not allowed - to deal with a disease that affects them. Other members can then test, evaluate and, if necessary, further develop the proposals", 2015*

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**THE INDEPENDENT (UK)**



*"Patient Innovation is a website set up by a group at the Católica Lisbon School of Business and Economics. It allows patients who've developed their own solutions for their illnesses to share what they've learned or invented", 2016*

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**VIRGIN (USA)**



*"Patient Innovation is an impressive platform that helps patents drive innovation to find treatment options for their health problems. Patients often develop valuable solutions to help them cope with their disease. In some cases, they saved their own lives", 2014*

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**MIAMI HERALD (USA)**

**The Miami Herald**

*"The SHOWER SHIRT® Co was the only American-based organization receiving the award for 'Patient Innovation,' winners were chosen from a pool of more than 200 innovation eligible products. The advisory board, a combination of faculty professors from the U.S. and Europe selected six winners based on Caregiver, Collaborator, and Patient Innovation", 2015*



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PATIENT INNOVATION IN **P3, PORTUGAL, 2013**

**PATIENT INNOVATION IS  
A SOCIAL NETWORK FOR  
PATIENTS**

**Pedro Oliveira created a social network in which it is possible to share experiences about a disease that you have or already had. The aim is the mutual aid and sharing of knowledge**

"During our research, we realized that there is an excessive amount of solutions, either therapies or medical equipment, which are developed by the patients",

explains Pedro Oliveira, CATÓLICA-LISBON and Massachusetts Institute of Technology (MIT) researcher. What happens is that "the patients who are living with chronic diseases, for example, find a way to live better with their own problem". For this reason, Pedro Oliveira and his multidisciplinary team decided to find "a 'mechanism' to facilitate the exchange of solutions between patients", which promotes the sharing of these innovative methods. Thus, Patient Innovation was born, a social network aimed at helping those who have or have had serious illnesses.

Then you just start sharing information, photos and other content on a given disease.

To access the content that others publish, there is a tool that allows the search by disease name or by symptoms. The language is automatic, taking into account the preference of the user, and everything is translated. For the most skeptical, Pedro Oliveira gives an example: an English engineer had a problem in the aortic artery, without solution. He developed the valve himself that was implemented successfully by his doctor in 2004, and solved the problem. In fact, the valve has already been used in more than 100 patients all over the world.

**29 HELENA AND PEDRO**

*Helena Canhão and Pedro Oliveira,  
Patient Innovation project leaders.*

(CONT.)

## **A UNIVERSAL PLATFORM**

Another of the purpose is, precisely, that the platform is universal. For this reason, the team now tries to get around some bureaucratic problems and legal issues (mainly in the United States) in order to launch the network after the summer.

Still, the platform is not stopped. Patients of various partner institutions from five countries are already registered and share content so that the social network is already launched with some

information. In Portugal, the partnership was carried out with the National Association of Mental and Rare Diseases, Raríssimas, the Diabetic Protective Association in Portugal, which will also control, somehow, the content shared online by the patients. "We will not edit what people say, but if eventually, someone suggests a dangerous idea, we can suggest a change and advise people", Pedro says.

Another of the path to follow will be to enable patients to "develop their own tests and clinical trials. Usually, these tests are very

expensive, because as it is about rare diseases, there is some difficulty in recruiting enough patients", explains the researcher.

This sharing of information and contacts may be helpful in that sense. After all, just in Europe, there are 30 million people with rare diseases.

## **PATIENT INNOVATION IN MEDGADGET**

### **HEALTHCARE STARTUP SOCIETY CONFERENCE AND AWARDS CEREMONY IN LONDON**

Hosted by the UK-based Healthcare Startup Society, the conference and awards ceremony on December 17<sup>th</sup> brought together nearly 200 participants, including some big name medtech innovators and startups, along with tech experts, VCs, students, and "doctorpreneurs." Attendees had traveled to the conference from as far as Silicon Valley, and while the December weather in London could never rival California, the fantastic venue in Kensington did boast resident flamingos!

Guest speakers covered an impressive array of medtech subjects throughout the day. The issue of funding, from both sides of the table, was examined with talks by the teams behind crowd source platform Crowdcube and surgical simulator company Touch Surgery.

Patient Innovation – Patient Innovation is based in Portugal but allows patients and caregivers around the world to connect. Users create and share solutions for health-related problems that they have developed independently or with collaborators. Founded in 2014, Patient Innovation boasts over 650 solutions from more than 40 countries, with solutions ranging from 3D-printed prosthetics to clothing and smartphones apps, all presented in step-by-step guides and how-to videos.



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#### **AWARD**

*Non-profit Startup of The Year Award*

PATIENT INNOVATION IN **MEDSHOP****YOUR FAVOURITE MEDICAL RESOURCE**

As a kid, I spent three and a half hours a week mowing my parent's lawn. Usually, it was right about the time my friends were loading into my neighbor's car to enjoy a summer Saturday. Spend the better part of a Saturday in arduous labor and you turn into a theoretical engineer.

Although I never possessed the technical skill or courage to modify my parents mower, I had perfect designs in my head. I would cut mowing time by 66% with folding blades on each side, connected to the central axle via belts. It was beautiful, but the idea never left my head until just now.

In 2013, a man from Massachusetts, Paul McCarthy, decided he wasn't going to allow his son, Leon, to go through life without the use of his hand. The boy was born without fingers on his left hand. Unlike me, with my ambitions of modding the family mower, McCarthy didn't take the situation sitting down. He turned to the internet for plans, and found a video made by Ivan Owen, an American puppeteer and special effects artist who had sort of fallen into creating 3D printed prosthetics. McCarthy was inspired by Owen's video, where his simple invention allowed for a 5-year-old boy to use a prosthetic limb for his son, Leon. Within months they had a working prosthetic. McCarthy gets "Dad of year" for sure.

With enough frustration and enough time online, we can all probably find uncommon solutions for life's little challenges. But who has the time?

***"Patient Innovation (PI) helps professionals to further empower their patients with a network full of growing solutions that are simple, organized and genius"***

Especially for medical patients, who may not have the resources or energy to spend time searching. What are they to do?

What if there was a centralized place for innovative ideas that could revolutionize patient's lives? That would be invaluable.

Good news. Someone has already created this site.

It's aimed at patients, but medical professionals may also find it valuable. It offers patients alternative resources for improving their quality of life. Patient Innovation (PI) helps professionals to further empower their patients with a network full of growing solutions that are simple, organized, and genius.

**31 LISA CRITES**

*Lisa Crites, one of the 1<sup>st</sup> Patient Innovation Awards winner, and her innovation - The Shower Shirt™.*

(CONT.)

Patient Innovation facilitates cross patient communication for simple solutions. Although the site management team is a collection of decorated professionals, the actual content of the site is patient and caregiver driven.

The goal, as PI puts it, “is a platform and social network that allows patients and caregivers to share their health solutions with other people.” Often times, solutions that work for one set of patients, can apply to other patients suffering through similar challenges, even thought they may not have been through the same exact treatment.

The site encourages users to share the simplest solutions, as it’s often the little things that make life more comfortable.

We’ll come back to some actual examples in a bit, but i’m thinking my modified lawnmower could have helped groundskeepers everywhere, if there had been something like PI for lawn care back then.

Their platform challenge is the meat and potatoes of their unique vision, and worth reading in its entirety: “We are driven by a fundamental challenge: to create a wide social network to connect patients and enable sharing of solutions, treatments, devices, and other relevant knowledge”.

The result is Patient Innovation, a place where patients and those who care about them can share and access useful and otherwise unknown solutions to cope with their diseases. But we wish to go even further.

We want the medical and research communities on board, giving feedback and contributing

towards what we expect will become a virtual incubator for solutions that can be developed to answer any patient’s needs.”

## **THE SOLUTIONS ARE GENIUS**

One very interesting innovation on the site is the Shower Shirt™. It is a post surgical water-resistant garment, which was dreamt up by a patient who had undergone a bilateral mastectomy.

With a standard recovery time of 7-10 days, not showering wasn’t an option, and the plastic bags she was using weren’t working very well. So, the Shower Shirt was born. True to the site’s mission, the Shower Shirt™ works for more than just post-mastectomy patients. There are at least 11 other candidates who benefit from this medical equipment. It is simple, inexpensive and it matters to patients. Earle Dickson is probably the most famous case of patient innovation. He was a caregiver for his wife, Josephine, who frequently cut herself in the kitchen. Dickson’s prototype, a piece of gauze placed in the middle of a strip of adhesive tape, became the template of an industry which still lives: Band Aids. You many have heard of them!

## **THE LIBRARY OF INFORMATION IS ORGANIZED**

Getting started is very simple: users register, find their patient group and start sharing their solutions. I signed up by simply connecting to my Facebook account, clicking on one button, and *voilà!*

I was in. The first option is a large search bar, and then just below it are the categories of conditions, symptoms, locations, activities, devices and therapies.

Searching for solutions is as simple as either navigating to your patient group or using the search features, standard on most pages. For my test run, I clicked on “location”, navigated to leg (since I have knee pain from all that lawn mowing), and found five solutions. While nothing specifically matched my current situation, which really isn’t that bad, I bookmarked the site for Mobilegs in case things worsen. Mobilegs is a genius improvement on crutches.

## **THE LIBRARY OF INFORMATION IS GROWING EVERY DAY**

Once you register, you can also set up your notifications to receive updates. Because PI is an evolving database you’ll want to stay connected. Although there is already a ton of valuable information there, you can imagine that over time the library could grow immensely. That’s just what PI is hoping for. You can also connect with Patient Innovation on Facebook, Twitter (@PatientInov) and YouTube (various languages represented) if you prefer not to receive emails. In the long run, the more connected you are, the better. PI is well connected themselves, with organizations like Carnegie Mellon.



# Patient Innovation Team



*“I’m so proud to know the Patient Innovation team, both personally and professionally. It’s so exciting to see the Patient Innovation popularity to grow.”*

— **Lisa Crites**

CREATOR OF THE SHOWER SHIRT™  
1<sup>st</sup> PATIENT INNOVATION AWARD WINNER

# Main team

## » Pedro Oliveira, Ph.D

PATIENT INNOVATION FOUNDER,  
PRINCIPAL INVESTIGATOR AND PROJECT LEADER



Pedro Oliveira is founder and project leader of Patient Innovation. He is an Associate Professor at CATÓLICA-LISBON School of Business & Economics, where he works as Senior Associate Dean for Faculty and Research and as former Academic Director of the Lisbon MBA. He was an International Faculty Fellow at MIT-Sloan. Pedro received his Ph.D from The University of North Carolina at Chapel Hill and both his MSc and “licenciatura” from IST, Lisbon.

## » Helena Canhão, MD, Ph.D

CHIEF MEDICAL OFFICER AND  
PROJECT LEADER



Helena is a Professor at Nova Medical School where she is also the Principal Investigator of the EpiDoc Unit at CEDOC, the Chronic Diseases Research Centre at Nova Medical School. She graduated (both Ph.D and Habilitation) in Medicine (Rheumatology) from Lisbon School of Medicine, University of Lisbon. She also got a Master of Medical Sciences from Harvard Medical School, University of Harvard.

## » Leid Zejnilovic, Ph.D

RESEARCH AND OPERATIONS OFFICER



Leid is an Assistant Professor at Nova School of Business and Economics. Leid received his dual Ph.D degree in Strategy, Entrepreneurship and Technological Change from Carnegie Mellon University and CATÓLICA-LISBON, his MSc in Information Technology from Dzemal Bijedic University and his BSc in Telecommunications from the University of Sarajevo.

## » Salomé Azevedo

PLATFORM MANAGER



Salomé is a Teaching Assistant (Operations Management) at CATÓLICA-LISBON School of Business & Economics. She did an internship at Carnegie Mellon University's Engineering and Public Policy Department. She has a Masters degree in Biomedical Engineering from Instituto Superior Técnico, Lisbon.

## » Ana Duarte

COMMUNICATION MANAGER



Ana is the Communication Manager at Patient Innovation. Ana is also responsible for searching and analyzing solutions for the platform. Ana has a BSc in Communication Sciences from Universidade da Beira Interior and a Master's degree in the same area from Universidade do Porto.

## » Patrícia Rodrigues

DIGITAL MARKETING ADVISOR



Patrícia did an Executive Advanced-Graduation program in Innovation Management and Entrepreneurship at CATÓLICA-LISBON. She has a lot of experience working in User Experience, Digital Marketing, Strategy and Innovation.

## » Maria João Gonçalves, MD

MEMBER OF THE MEDICAL TEAM



Maria João Gonçalves graduated in Medicine from the Universidade de Coimbra and is a rheumatologist at the Hospital de Santa Maria, Lisbon. Maria João was a fellow in the Rheumatology Department of the University College of London.

## » Miguel Nunes, MD

MEMBER OF THE MEDICAL TEAM



Miguel Nunes graduated in Medicine at Universidade da Beira Interior, having concluded his specialty in Stomatology, at Centro Hospitalar Lisboa Norte, where he works. He was always interested in the business world and entrepreneurship, having founded Blocomed®, in order to bring a surgery kit he developed for students to the market.

## » Sofia Couto da Rocha

MEMBER OF THE MEDICAL TEAM



Doctor who got a degree at Nova Medical School, third year internet at Intern Medicine, CHALGARVE. MBA by The Lisbon MBA. Degree "licenciada" in Minor Science Politics, by FCSH, and at Design by LCF/CSM. Founder of the startup HealthTech&Design. PTCsRT from Harvard Medical School with FCT. President of the commission of Technologies of Information in Health at the Health Parliament Portugal.

### PREVIOUS PATIENT INNOVATION TEAM MEMBERS:

João Pedro Covas • Inês Viegas • Diana Nunes  
• Pierre Gein • Carlos Henriques • Tomás Fidelis  
• Patrícia Pereira • Rita Oliveira • Marina Duarte  
• Sofia Esménio • Tiago Ramalho • Teresa Fernandes  
• Rita Aroeira • Wendeline van der Feltz  
• Yulia Aleksandrova • Viktoriia Shcherbatiuk  
• Alexandra Ferreira • Matilde Czernin



*Advisory Board  
team members*

**» Richard Roberts**

CHIEF SCIENTIFIC OFFICER, NEW ENGLAND BIOLABS • NOBEL LAUREATE IN PHYSIOLOGY OR MEDICINE 1993

Sir Richard Roberts is the Chief Scientific Officer at New England Biolabs, a molecular biology reagent company located in Beverly, Massachusetts. Sir Richard Roberts was awarded the Nobel Prize in Medicine in 1993 for the discovery of split genes of RNA splicing and his development of restriction enzymes as molecular biology tools. This discovery led to decisive progress in many fields including cancer research.

**» Eric von Hippel**

PROFESSOR, MIT SLOAN SCHOOL OF MANAGEMENT

Prof. Eric von Hippel is the T. Wilson (1953) Professor of Management of Innovation and Engineering Systems at the MIT Sloan School of Management. His research discovers and explores patterns in the sources of innovation and develops new processes to improve the innovation process. In November 2015 Prof. Eric von Hippel passed 50 000 citations milestone on Google Scholar.

**» Aaron Ciechanover**

PROFESSOR, TECHNION-ISRAEL INSTITUTE OF TECHNOLOGY, NOBEL LAUREATE IN CHEMISTRY 2004

Prof. Aaron Ciechanover is a Distinguished Professor in the Technion-Israel Institute of Technology in Haifa. Ciechanover is a member (Foreign) of the National Academy of Sciences of the USA and the Israeli Academy of Sciences and Humanities, among others. Prof. Aaron Ciechanover received the 2000 Albert Lasker Award and the Nobel Prize in Chemistry in 2004 for the discovery of the ubiquitin system and its importance as an important platform for drug development.

**» Katherine Strandburg**

PROFESSOR, NEW YORK UNIVERSITY SCHOOL OF LAW

Prof. Katherine Strandburg is a Professor of Law at NYU School of Law. She is an expert in patent law, innovation policy, and information privacy law. Strandburg's research considers the implications of user and collaborative innovation for patent law and of "big data" for privacy law. Strandburg clerked for Judge Richard Cudahy of the US Court of Appeals for the Seventh Circuit.

**» Robert Langer**

PROFESSOR, MIT

Prof. Robert Langer is a leading chemical engineer and entrepreneur. He is one of the 11 Institute Professors at MIT, the highest honor that can be awarded to a faculty member. Langer is an internationally acclaimed inventor and engineer, with over 2 000 patents and published articles. He is a pioneer in drug delivery, tissue engineering, and nanotechnology.

**» Lee Fleming**

PROFESSOR, UNIVERSITY OF CALIFORNIA, BERKELEY

Prof. Lee Fleming is a Professor at University of California, Berkeley and the Faculty Director of the Coleman Fung Institute of Engineering Leadership. His research investigates how managers can increase their organization's chances of inventing a breakthrough, through types of collaboration, the integration of scientific and empirical search strategies, and the recombination of diverse technologies.



# *Advisory Board meetings*

The Patient Innovation team meets every year with its Advisory Board (AB) members.

In these meetings, the Patient Innovation project is discussed: an evaluation about what the project has accomplished so far is undertaken and the ideas and prospects for the future are also debated with our advisors. So far, there have been three meetings with the AB.

On February 3<sup>rd</sup> 2014 the Patient Innovation team met with its AB for the first time at MIT Sloan, Boston, USA, with: Lee Fleming, Robert Langer, Richard Roberts, Katherine Strandburg and Eric von Hippel. In this meeting, Patient Innovation received some strategic advices, and some structural changes were made, including the possibility of allowing users to see solutions without having to register and the removal of any drug and food related content from the platform.

**In these meetings, the Patient Innovation project is discussed: an evaluation about what the project has accomplished so far is undertaken, and the ideas and prospects for the future are also debated with our advisors**

On November 1<sup>st</sup> 2014 the Patient Innovation team met again with the AB at MIT Sloan in Boston. It was another inspiring meeting. The 30 semi-finalists of the PI Awards were presented and six winners were selected by the AB.

The third meeting with the AB was on January 28<sup>th</sup> 2016. The PI team met again with the AB at MIT to discuss the progress and the future of the project, as well as to select the winners of the 2<sup>nd</sup> PI Awards.

This time the AB selected seven winners, including the new category - Serial Patient Innovation - for a patient who developed several innovations and also created a website to share his solutions with others.

#### 32 2014 MEETING

*The Patient Innovation team in a meeting with the Advisory Board, on November 2015.*

#### 33 2016 MEETING

*The Patient Innovation team in a meeting with the Advisory Board, on January 2016.*



A large, stylized smiley face is the background of the page. It is composed of a thick, dark red curved line for the mouth and a lighter red circular area for the face. Inside the face, there are several smaller, rounded rectangular shapes in a darker red, arranged to suggest eyes and a nose.

*Supporters*



**Carliss  
Baldwin**

PROFESSOR, HARVARD  
BUSINESS SCHOOL  
HARVARD UNIVERSITY



**James Boyle**

PROFESSOR, SCHOOL OF  
LAW DUKE UNIVERSITY



**António  
Câmara**

CEO, YDREAMS



**Maria Carmo-  
Fonseca**

PRESIDENT, INSTITUTO  
DE MEDICINA  
MOLECULAR  
PROFESSOR, FMUL



**Alexandre  
Castro Caldas**

PROFESSOR AND  
DIRECTOR, INSTITUTO  
DE CIÊNCIAS DA  
SAÚDE, UNIVERSIDADE  
CATÓLICA PORTUGUESA



**António  
Coutinho**

COORDINATOR,  
CONSELHO NACIONAL  
DE CIÊNCIA E  
TECNOLOGIA



**Joi Ito**

DIRECTOR, MIT MEDIA  
LAB



**Lawrence  
Lessig**

PROFESSOR, HARVARD  
LAW SCHOOL  
HARVARD UNIVERSITY



**Kathrin  
Mösllein**

PROFESSOR,  
UNIVERSITÄT  
ERLANGEN-NÜRNBERG  
& HHL LEIPZIG



**José Fonseca  
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PROFESSOR, FORMER  
DEAN OF CATÓLICA-  
LISBON SCHOOL  
OF BUSINESS &  
ECONOMICS. DEAN  
OF IMPERIAL COLLEGE  
BUSINESS SCHOOL



**Artur Santos  
Silva**

PRESIDENT OF THE  
BOARD OF TRUSTEES  
OF THE CALOUSTE  
GULBENKIAN  
FOUNDATION



# Local Chapter Berlin





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## BERLIN

*The first Patient Innovation Local Chapter - Local Chapter Berlin.*

A Local Chapter (LC) of Patient Innovation (PI) is a non-profit collaborative association created between PI and an individual or a team from any part of the globe that showed interest in working with PI. The LC is established to specifically cover topics and subjects particularly relevant for a given domain of interest or a geographical region, and acts in compliance with PI values, goals and terms of service. The LC aims to serve the needs of a regional community of interest, in terms of:

- **PRESENTATION** of PI content in local languages;
- **PROMOTION** of the content in locally organized events;
- **SEARCH** and facilitation of content originating in the geographical region or the domain of interest, according to the terms and services of the PI platform;

• **PROVISION** of help to patients, caregivers and collaborators in the domain or geographical region of interest, in terms of usage of PI platform.

The first Patient Innovation Local Chapter was founded in Berlin, with the following team members:

- Ana Luísa Marcelino;
- Greta Pierchalla;
- Iris von Wunsch de Teruel;
- Adriana Perdigão;
- Cynthia de Carvalho Fischer;
- Carolina Czichos;
- Dominik Soll;
- Maria Salazar de Sousa Mann.

# Partnerships

Our project can only achieve its full potential if a large number of patients and caregivers are attracted to the platform. For that reason, it is important to involve patient associations in our initiative. We are very happy with the positive response from patient groups and associations of various types of diseases, and from different geographical ranges across all around the world. We have a portfolio of partner associations in Australia, Brazil, Malaysia, Portugal, Spain, and the UK, among others.



These are the associations that already signed collaboration agreements with Patient Innovation:



*What our*  
*Community*  
*members*  
*have been*  
*saying*



*“I was thinking about building a platform like Patient Innovation myself. I’m very glad the Patient Innovation team did it and invited me to be a part of it.”*

**Giesbert Nijhuis**  
PATIENT (TETRAPLEGIA)

*“I care about people, and always want to do something that can make their lives easier and happier. I didn’t know Patient Innovation, but I was really happy when they asked me to join the platform.”*

**Bhuvnesh Tanwar**  
COLLABORATOR

*“I’m deeply grateful to get to know the Patient Innovation team. They have my admiration. I feel like I’m riding on the shoulders of giants!”*



**Louis Plante**  
PATIENT (CYSTIC FIBROSIS)

**Luis Quaresma**  
PATIENT (SPINA BIFIDA)

*“We often feel that patients have solutions that are not being shared with the community. But they can only be helpful when shared. Patient Innovation helps with this.”*



**Doron Somer**  
CAREGIVER (AUTISM)

*“Thank you Patient Innovation. You are an amazing group. Thank you so much for our time together. We will cherish it in our hearts forever!”*

*“The Patient Innovation platform is great because it’s a way to help caregivers share their solutions and experience with each other. This can help improve our children’s quality of life.”*

**Maria do Céu Ramalhete**  
CAREGIVER (OSTEOGENESIS IMPERFECTA)

*Thank you.*

*Keep sharing  
your ideas,  
solutions,*

*prototypes and  
innovations.  
Be part of a new  
revolution.*



*Celebrating 3 Years of Patient Innovation,  
Report 2014-2017*

*Patient Innovation  
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[youtube.com/c/patientinnovationpi](https://youtube.com/c/patientinnovationpi)*

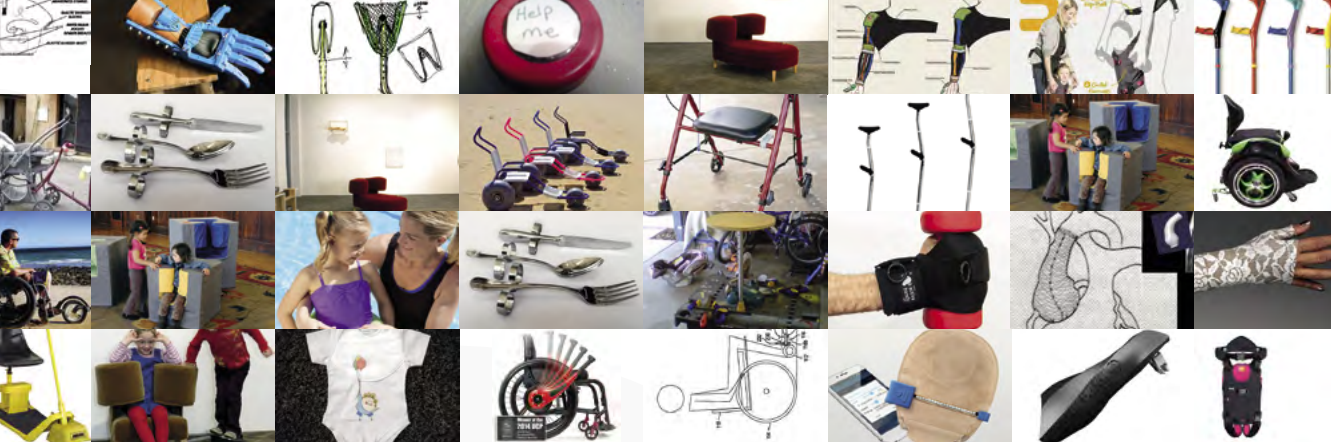
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COM O ALTO PATROCÍNIO  
DE SUA EXCELÊNCIA  
UNDER THE HIGH PATRONAGE OF THE  
PRESIDENT OF THE PORTUGUESE REPUBLIC

