



# Patient Innovation

SHARING SOLUTIONS, IMPROVING LIFE



RESEARCH IN THE FIELD OF  
**OPEN AND USER INNOVATION**  
HAS SHOWN THAT **PATIENTS**  
OF CHRONIC DISEASES HAVE  
**DEVELOPED** A SIGNIFICANT  
NUMBER OF INNOVATIVE  
**TREATMENTS AND MEDICAL**  
**DEVICES** TO HELP THEM COPE  
WITH THEIR CONDITION AND  
INDIVIDUAL NEEDS.



Patients of chronic diseases have to deal with long-lasting conditions and everyday challenges. They frequently develop valuable solutions to improve their quality of life and even treat their own disease, sometimes saving their own lives! **What if they could end up saving the lives of others?**

These innovations usually occur behind closed doors and might never be known or used by anyone else. However, if successful innovations and knowledge were shared with other patients with similar needs, it could improve the lives of many others.

Potentially a game changer in the healthcare industry

## Potential benefits

The sharing of innovative treatments and medical devices developed by patients can not only be of very high value to other patients — it can potentially be a game changer in the healthcare industry.

Total healthcare spending is rising worldwide. Reductions in the cost of treatment development and the diffusion of novel treatments of clinical value would be a major boon to suffering patients as well as to governments. Helping patients help themselves by sharing patient-led medical innovation could save money for everyone.

# Our vision

THE PATIENT INNOVATION PLATFORM



Each patient or caregiver is a potential innovator.

We are driven to create a non-profit social network and platform to connect patients and enable sharing of medical treatments, devices and knowledge, otherwise unknown to some patients.

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## How does it work ?

The Patient Innovation Platform is an international, multilingual, totally free-of-charge venue for patients and caregivers of any disease to share their innovations within the community.



Importantly, the platform includes rare diseases. These diseases get less research attention from conventional medicine and pharmaceutical companies.

The platform allows searches by disease and symptoms. It is available online at [www.patient-innovation.com](http://www.patient-innovation.com) and through a Facebook application.

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



## Research and management team

The Patient Innovation Platform has resulted from the joint research and international cooperation of scholars (from the health sciences, management, economics, engineering and law), healthcare practitioners and institutions that are committed to help promote knowledge and solutions that can improve patients' well being.



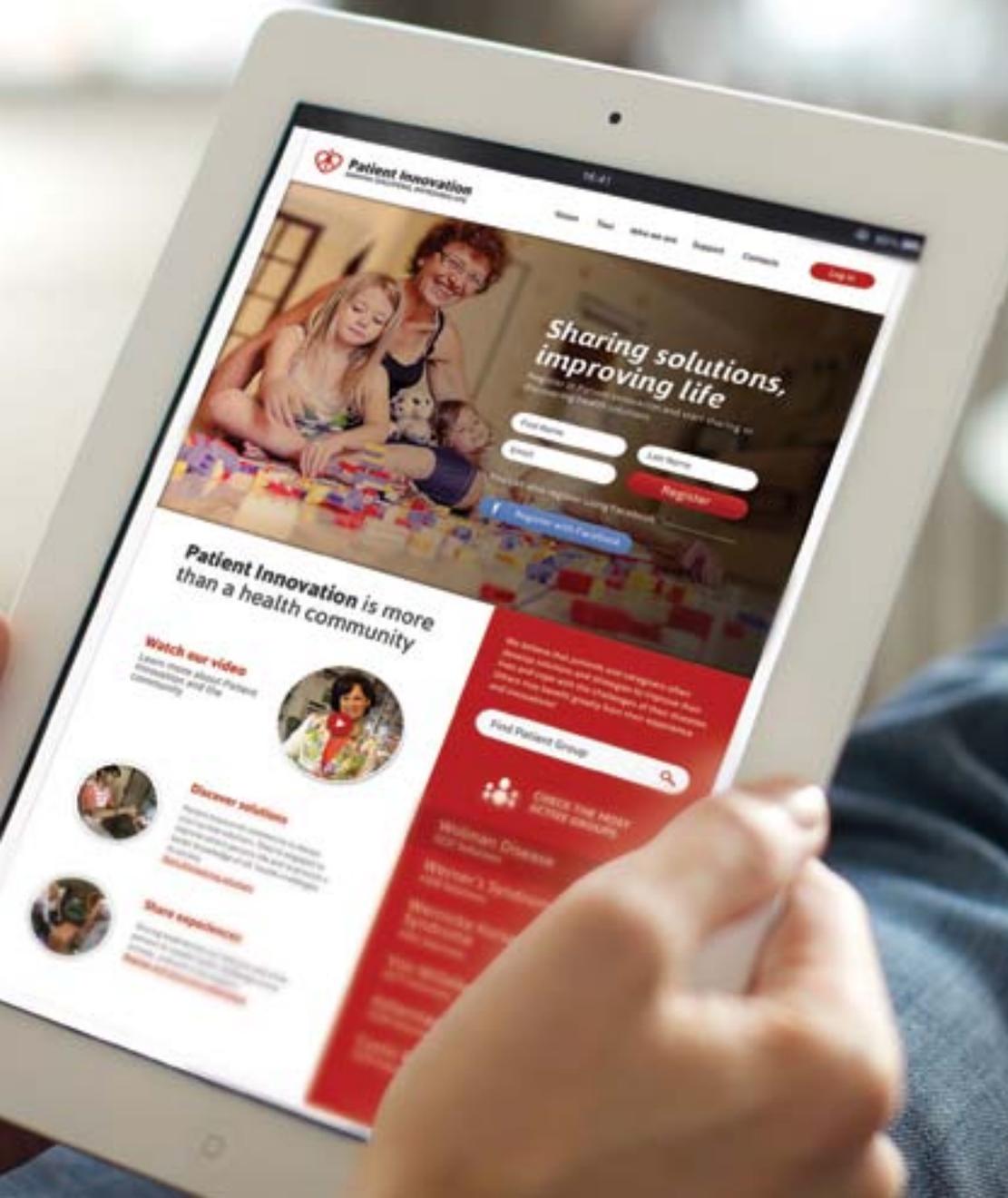
Even the most simple solutions can change the day-to-day lives of patients and caregivers.

## SOME SOLUTIONS OUR USERS SHARED

**Mariana** has **cri du chat syndrome** and patients with this pathology usually have an obsessive attachment to objects. She has a fixation with hair, especially when she is angry, and she pulls hers and other people's hair out. Her parents observed: "When our hair is wet, she doesn't like to touch it and doesn't try to pull it out. Because of that, we discovered that if we **put hair gel on her**, she stops. Now, when she is angry, we put some hair gel on her and she stops focusing on it and doesn't pull it out".

**Luis** has **spina bifida**. One symptom of this disease is a lack of sensitivity in the legs and feet, which easily creates wounds when dried too hard with towels. To prevent this, Luis says: "**I put toilet paper around and in the middle of my toes**, which dries them without friction and wounds."

**Gonçalo**, who suffers from **Angelman syndrome**, has a sleep disorder and is obsessed with his father. When his father is absent for a few days, Gonçalo has sleepless nights. His mother came up with a strategy: "**I filled up my husband's clothes with foam, creating a whole doll**. I keep this doll for the moments when my husband is away, so that Gonçalo remembers his father's smell and stays calm and snug in his bed."



# Advisory Board



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Professor, Technion-Israel  
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Professor, MIT Sloan School of  
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**Richard Roberts**  
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**Francisco Veloso**  
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Business & Economics  
Professor, Carnegie Mellon University



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

## Sir Richard Roberts

NOBEL LAUREATE IN PHYSIOLOGY OR MEDICINE 1993

“I think this is a very creative and useful idea, because when people are faced with a difficult situation they often come up with quite innovative solutions all by themselves, but not everybody comes up with the same one. If there’s a forum whereby they can share their solutions, then that can be very helpful to others in the same situation, who didn’t find any solution. Even better, some people will look and realize they could combine some of these ideas, or add a new wrinkle of their own, and come up with an even more innovative and useful solution. This is an outstanding use of social media that should help many disadvantaged people who desperately seek ways to improve their quality of life!”

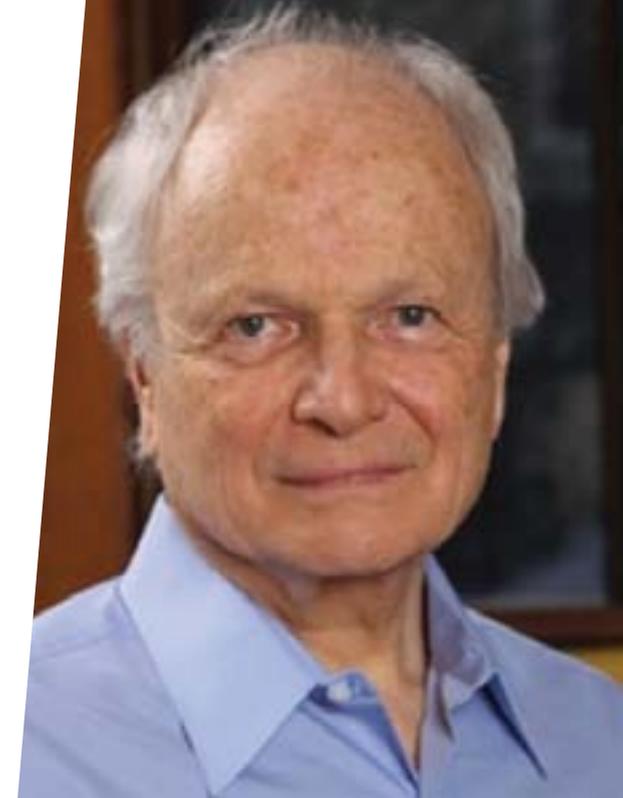
## Prof. Eric von Hippel

MIT SLOAN SCHOOL OF MANAGEMENT

“Research in the field of User Innovation has shown that millions of individuals create products and services they need for their own use. Many of these have great value to others as well. Research by Professor Oliveira documents that medical patients are also innovators, developing innovations to help them manage and maybe even cure the diseases that afflict them.

In my view, the Patient Innovation Platform is a project with potentially very great social value. It will facilitate sharing of solutions developed by patients that would otherwise be lost. It will also contain tools to enable low-cost statistical evaluation of solution effectiveness by patients themselves. I support this project with great enthusiasm.”

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





“Patients and caregivers are innovators in their own right”

**Prof. Katherine J. Strandburg**  
NEW YORK UNIVERSITY SCHOOL OF LAW

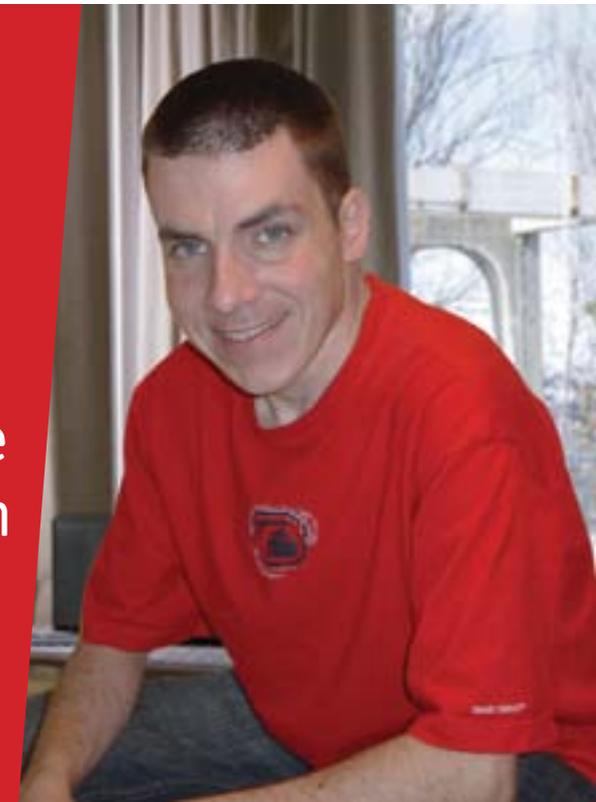
“This platform has enormous potential to improve the lives of rare disease sufferers. Patient and caregiver communities already work proactively to educate patients and physicians, organize support networks, pursue regulatory reform, and confront providers about treatment availability and cost. They advocate increased research funding and maintain patient registries. Policymakers have begun to recognize that rare disease patients are indispensable research collaborators and to design research strategies accordingly. This initiative goes further, recognizing that patients and caregivers are innovators in their own right and using IT to facilitate the sharing, improvement, and evaluation of their innovations.”

**Louis Plante**

CYSTIC FIBROSIS PATIENT AND INVENTOR

“Having lived with my disease for many years, I was fortunate enough to have understood how to improve my quality of life by creating a solution to my problem, the “electro-acoustical transducer”. Sharing my invention with many other patients is important for me and this platform seems to be an amazing tool to guys like me, who had a serious health condition and managed to solve it by themselves.”

“Sharing my invention with many other patients is important for me and this platform seems to be an amazing tool”





“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”

## **Prof. Francisco Veloso**

DEAN, CATÓLICA-LISBON SCHOOL OF BUSINESS AND ECONOMICS  
PROFESSOR, CARNEGIE MELLON UNIVERSITY

“Católica-Lisbon is proudly committed to supporting this international research project and solution sharing platform. 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. Patient Innovation is also the result of joint interdisciplinary research collaboration with a variety of leading scholars at MIT, Carnegie Mellon and others, to whom we are grateful for their deep involvement and support.”

## **Paula Brito e Costa**

FOUNDER AND PRESIDENT OF  
RARÍSSIMAS, A NATIONAL ASSOCIATION FOR  
RARE DISEASES



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

## **Pedro Oliveira (Project Leader)**

PROFESSOR, CATÓLICA-LISBON  
INTERNATIONAL FACULTY FELLOW, MIT SLOAN  
SCHOOL OF MANAGEMENT



“Patient Innovation is a joint effort of people with high academic and personal interest in catalyzing knowledge sharing among patients and further understanding the innovation and diffusion processes. We are thankful to the patients, practitioners, academic colleagues and sponsors who have generously supported our project.”



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For further information, please contact  
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[www.patient-innovation.com](http://www.patient-innovation.com)