



Patient Innovation

SHARING SOLUTIONS, IMPROVING LIFE

When patients set out to help themselves and end up helping many

<https://patient-innovation.com/>

<https://www.facebook.com/PatientInnov>

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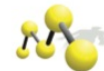
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Patients of chronic diseases often innovate

Research documents that patients often innovate by developing new solutions, sometime all by themselves, to help them manage the diseases that afflict them.



Often patients set out to help themselves and end up helping many



Examples of patient innovations (1)

Temple Grandin (high-functioning autism)

Invented the hug machine to calm people who are overly sensitive to human touch



Source: Oliveira, von Hippel and DeMonaco (2011)

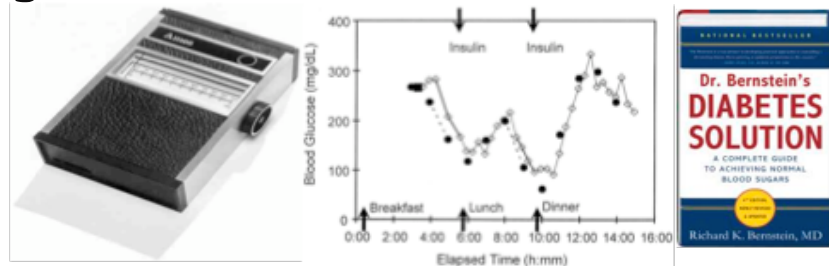


Examples of patient innovations (2)

Richard Bernstein and diabetes



- ▶ Type 1 diabetes patient (entered med school when he turned 45 y.o.)
- ▶ Began measuring blood sugar 5 times/day and refined his insulin and diet regimen to the point that they were normal around the clock
- ▶ The first individual to self-monitor his blood sugar





Examples of patient innovations (3)

BLOB a small, portable device that discreetly delivers insulin (injection)

Why didn't you share your device with doctors?

“Because my solution is oriented to patients everyday use, and, as a diabetic patient, I think that the **patients are the ones that have the knowledge in the topic of everyday use of the device.** I consulted the technical aspects with engineers, because I know my doctor doesn't really know about insulin maintenance.”

Diabetes patient and innovator

BLOB MINI dispositivo recargable para insulina





Examples of patient innovations (4)

Use of trampolines by children



Our questions: Did a patient or patient's family have any involvement in the initiation of the study?

Dr.J. K. Stanghelle: *“The answer is YES ! We were performing different studies with physical exercise and cystic fibrosis (CF) at that time, and this was a time when it became growing interest for such therapy, contrary to "normal medicine" these days. We were discussing in several fora what kind of exercise that could be fun and effective for children with CF, and **we got to hear about a young girl with CF that had a trampoline that she wanted to use many times a day for long times, and the parents observed that she didn't need to use extra treatment for lung drainage in addition.**”*



Examples of patient innovations (5)

Chest percussion with electrical percussor

“My daughter, 26 with CF, depended for most of her life on us, her parents to do her chest physiotherapy. So her independence was constantly compromised and she hated it. On other hand, we not always delivered the best physiotherapy, simply because were tired, or didn't have all this time required or were sick. Sure, you know all of this ... Many times I was thinking about a simple solution, which would deliver a good physiotherapy and wouldn't require a caregiver. And I am very happy, I could do it. My daughter uses my eper 100 (stands for electrical percussor, and 100 symbolizes all my percussion ideas which were never realized) all the time.

According to her it is much better than the human hand and she can do it alone. I got good reviews from the hospital for sick children in Toronto.

Hanna Boguslawska” Mother of Natalia and founder of eper ltd (March 2006)





The problem we identified - summary

- (i) Rate of innovations by patients is significant **but** could be increased (patients could use some help from others)

- (ii) Innovations rarely diffuse, innovators don't have incentives to diffuse and face a lot of resistance



Our project

An international, multilingual, open, free and non-profit platform and social network to facilitate the sharing of innovative solutions developed by patients or caregivers of any disease



“We are very excited about this project”

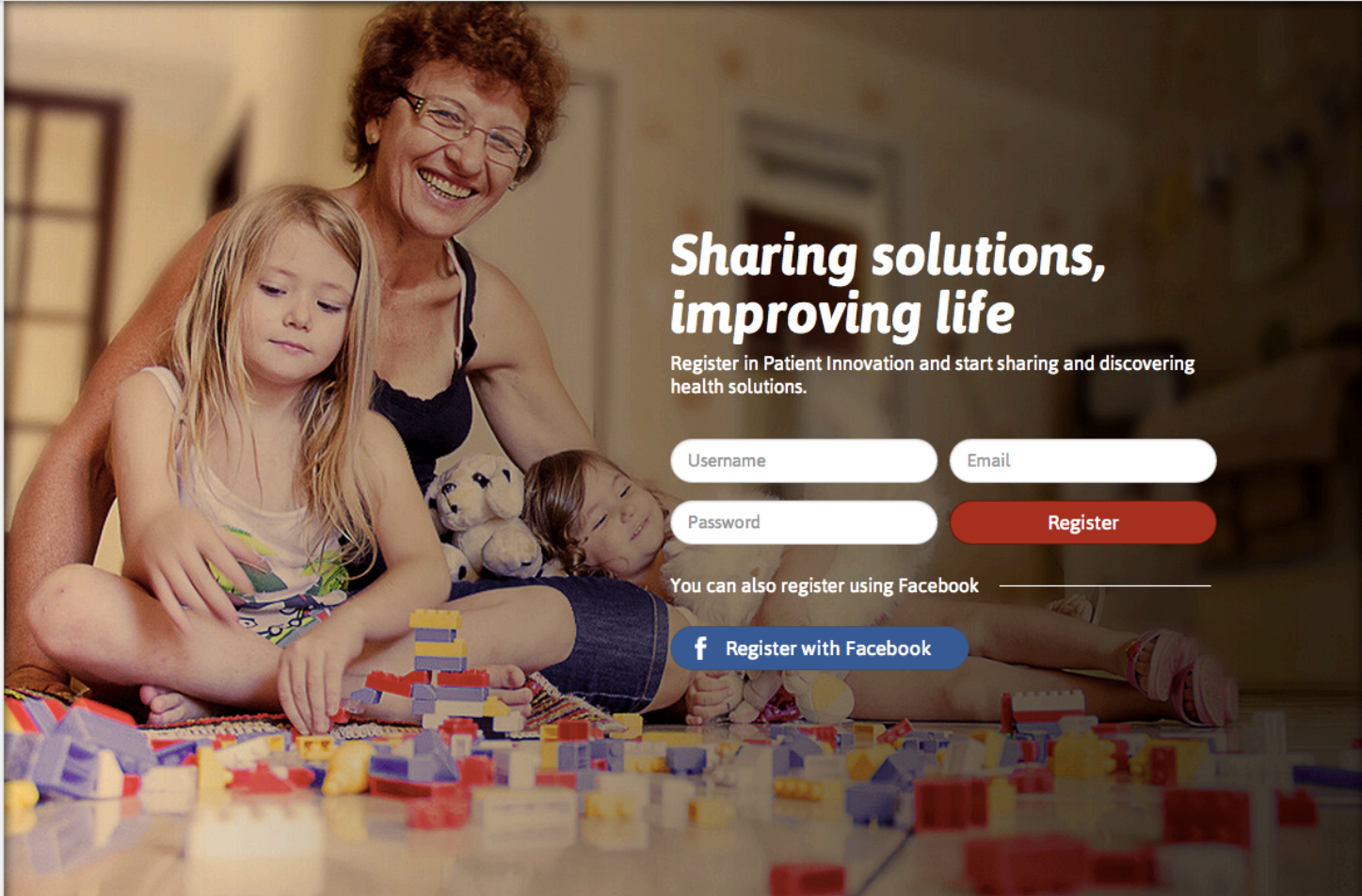


www.patient-innovation.com



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Sharing solutions, improving life

Register in Patient Innovation and start sharing and discovering health solutions.

You can also register using Facebook

We believe that patients and caregivers often develop



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

Sir Richard Roberts

NOBEL LAUREATE IN PHYSIOLOGY OR MEDICINE 1993

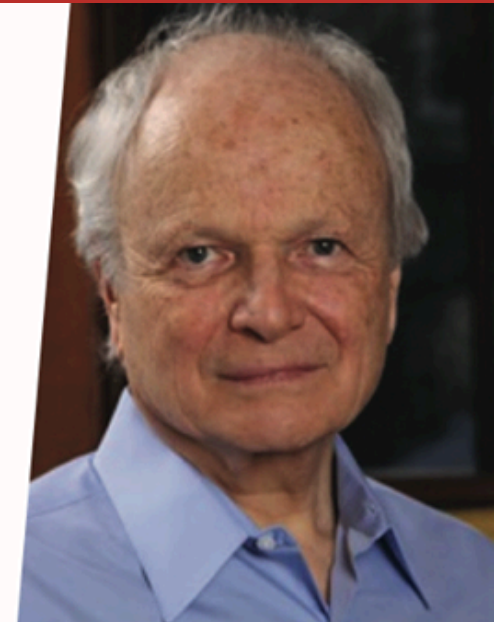
“I think this is a very creative and useful idea, because when people are faced with a difficult situation they often come up with quite innovative solutions all by themselves, but not everybody comes up with the same one. If there’s a forum whereby they can share their solutions, then that can be very 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”



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Outros Apoiantes



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The Patient Innovation Award



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1st Patient Innovation Award

Objective: To create awareness of patient innovation and encourage patients to actively search for solutions

What is eligible: Solutions developed by patient/caregiver/ collaborators to help them deal with the disease

Criteria: Best solutions are those with highest potential of helping other people deal with their diseases

Selection procedure:

1. Short list: PI team selects and ranks 10 finalists and prepares a small report to present to Advisory Board
2. Advisory Board selects favorites
3. PI Award winners are announced in a public session in Lisbon



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Thanks !

