Inventor Tal Golesworthy with the scar left by the operation to fit the aortic root sleeve (shown bottom right) he himself designed.

PHOTOGRAPH BY DAVE IMMS

Medical innovation isn't the preserve of doctors. Clever new ideas and solutions are coming from patients and carers.

The Self-Helpers

BY SORREL DOWNER

WHEN TAL GOLESWORTHY WAS TOLD HE NEEDED LIFE-SAVING heart surgery, his reaction was not what you might expect. Golesworthy has Marfan syndrome, a genetic condition affecting the strength and elasticity of body tissues, including blood vessels. Back in 1993, when he was living in Cheltenham, in the west of England, his doctor told him that a major artery in his heart, the aorta, was so enlarged that it would inevitably rupture unless he underwent major surgery.

"They talked through the surgical options," says Golesworthy, "and I was not interested. The operation really didn't look attractive." What he particularly didn't like was the prospect of having to be on blood-thinning medication after the operation, something that would prevent blood clots but present its own risks:

"I was riding motorbikes then, and skiing, so my whole lifestyle would have been affected."

By 2000, however, his condition had worsened. Realizing something had to be done, Golesworthy put his years of experience as a research and development engineer with the United Kingdom's National Coal Board to good use. He decided he would fix himself.

"Learning new stuff and developing new ideas, that was my job." A bulging aorta, he reckoned, was much like a bulging hydraulic hose: it needed external support. And wrapping something around the outside of the aorta would require a less invasive operation.

So Golesworthy subjected himself to a total of 30 hours in an MRI scanner, used 3D printing to create a physical replica of the faulty part of his heart (the aortic root), then used soft, porous textile mesh to make a sleeve to fit around it.

"Luckily, I'd done a lot of work with technical textiles, looking at filters for flue gases in coal-fire processes," he says.

Sheer determination, coupled with an original yet practical solution, won him the support of two leading cardiothoracic surgeons, and helped him raise the money to develop his idea. In May 2004, at the age of 47, he became the guinea pig for his own invention, the ExoVasc™ Personalised External Aortic Root Support (PEARS). The operation was a success—although he admits to feeling a little nervous in the run-up to the procedure.

Today, Golesworthy's invention has been used by surgeons in the United Kingdom, Ireland, Belgium, Czech Republic, New Zealand, and France, and is to be used in Poland and the Netherlands.

More than that, the story of Tal's invention has proved inspirational.

> **"I began finding all sorts of examples of innovation—some of them were developed by patients, others by caregivers."**

"I HAD HEARD TAL give a presentation and found it very interesting," says Dr. Pedro Oliveira. Oliveira is not a medical doctor but an associate professor at the Católica Lisbon School of Business & Economics in Lisbon, the capital of Portugal.

He had been the lead on an international research project investigating innovation in different industry sectors. "I began looking at health, and finding all sorts of examples of innovation—some of them were developed by patients, others by caregivers."

Not all of the ideas were sophisticated and scientific—far from it. In fact, it was the simplicity of one particular solution that was to inspire Oliveira.

During his research, he met Joaquina Teixeira, the mother of a six-year-old boy suffering from Angelman syndrome, a neurogenetic disorder affecting development. Despite years of treatments, her son had been confined to a wheelchair, unable to walk.

But at a children's party, Joaquina had watched him as he reached for the strings of helium-filled balloons floating around the room and it had given her an idea.

She hurried home and filled every room with bright-colored balloons. The results were extraordinary: the little boy stretched for them; before long he was standing up to grab them. Eventually, he was walking unaided.

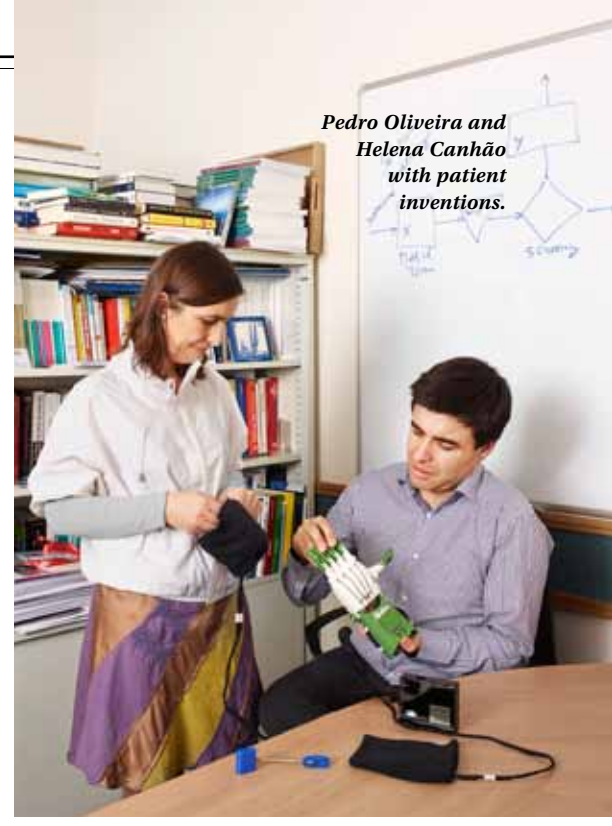
Oliveira realized that sharing this cheap and effective strategy would be enormously helpful for families of other children suffering from this rare disorder.

It got him thinking. Patients and carers around the world were coming up with ideas for coping with everything from Alzheimer's, Parkinson's, and paralysis to asthma and arthritis. If just a fraction of the best ideas could be shared, it could improve the quality of life for hundreds of thousands of people around the world.

Spurred by this thought, in 2014 he launched an online platform, calling it Patient Innovation.

Free to use, multilingual and global, the platform allows anyone to search for—and submit—suggestions, solutions, and advice on a wide range of medical conditions.

Oliveira's partner in the project is Professor Helena Canhão of the Nova Medical School in Lisbon. As chief medical officer, she is responsible for reviewing the ideas. User safety is of



Pedro Oliveira and Helena Canhão with patient inventions.

ANGELA MOORE

paramount importance, and there are strict submission guidelines. Half of the submissions are weeded out, says Canhão. "Nonetheless, we've been able to identify and medically approve 750 innovations, and there are 60,000 registered users submitting solutions or, as in the majority of cases, searching for solutions."

Among the ideas and inventions on the Patient Innovation platform is Tal Golesworthy's aortic root support. He was there to speak at Patient Innovation's launch event in Lisbon in 2014.

"I was overwhelmed, but not surprised, that so many great ideas were coming from all sorts of patients and carers, many of whom had very little professional expertise to assist them in their struggle," he says.

"These people may have no specific training, but they do have a need. As they say, necessity is the mother of invention."

PATIENT INNOVATION has built a distinguished advisory board that includes two Nobel laureates (the English biochemist Sir Richard R. Roberts and Israeli biologist Aaron Ciechanover), eminent professors of law, business, and bioengineering, and representatives from a broad spectrum of patient associations.

Some of Patient Innovation's inventors have devised very sophisticated solutions. Oliveira cites Amit Goffer from Israel, who was left quadriplegic after a car accident, but who went on to invent the most advanced powered exoskeleton on the market, a sort of wearable robot, helping people with lower-limb injuries to walk.

Others submit information on homemade gadgets and practical tips that are invaluable to others sharing similar challenges.

"These aren't solutions developed by medical scientists, but by normal people who generally have no specific training," says Oliveira. "What they do have, though, is a need. As they say, necessity is the mother of invention."

One of Oliveira's favorite examples is Michael Seres from England. Seres, who has Crohn's disease, was fitted with an ostomy bag following a bowel transplant in 2011.

"There's no easy way of knowing whether the bag is full or not, which is not nice, as you can imagine—and in a social situation you don't want to look. So Michael developed a sensor for the bag that communicates with his smartphone via Bluetooth. Now he just looks at his phone. And if the bag fills quickly there's an alarm telling him to change it."

Seres's Ostom-i™ alert sensor is now being sold across Europe and the United States. Its creation had a distinctly DIY flavor. "I bought some parts on eBay," says its inventor. "The main part was a flexible sensor strip that came from a Nintendo Wii glove."

Crohn's disease sufferer Michael Seres with his Ostom-i™ alert sensor.

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"There are five million people with ostomy bags," adds Oliveira. "It's hard to believe there was nothing like this available before."

Many ideas are very simple, yet very effective. Lisa Crites, an American newscaster, designed a waterproof cape, called the Shower Shirt™, that makes it easier for breast-cancer patients to shower after surgery—an idea she had after her own double mastectomy. British inventor Chris Peacock came up with the ergonomic handSteady™ cup after watching a family member with Parkinson's struggle to lift a mug without spilling its contents. The cup has a rotating handle that allows the cup to remain in an upright position.

Keen cook and rheumatoid arthritis sufferer Graham Drummond from New Zealand invented special kitchen knives and chopping boards to make preparing food less painful and considerably safer.

"As well as ideas that just need to be shared," says Oliveira, "there are early-stage innovations that are complex, which people can't develop themselves. So we are going to establish a lab—an incubator—to help patients and caregivers develop their ideas further, and commercialize them."

The multidisciplinary Patient Innovation team has the right connections to provide a matchmaking service, linking patient innovators—many of whom are housebound—with the necessary support. Oliveira has been canvassing the support of engineering schools, where students are

Breast cancer survivor Lisa Crites with her waterproof Shower Shirt™.

always keen to apply their skills to real-world projects.

Several hospitals have shown an interest in helping with the rigorous clinical trials required before products and treatments can be brought to market, and there are philanthropists and commercial investors ready to back the R&D phase.

The business connections are especially useful for the many innovators on the Patient Innovation platform who are still at school. Some of these youngsters are motivated by a desire to help family members; others have channeled their post-millennial geekiness and brilliant minds into tackling their own challenges.

The ideas include: a wearable sensor allowing caregivers to keep track of wandering Alzheimer's patients; an adaptor that allows car keys to be pushed and pulled rather than turned in a lock; and a robotic arm that responds to brain signals.

The young people with these clever ideas may not know how to develop them further and get them into production, but Patient Innovation can help.

"There's a Portuguese kid called Diogo Lopes," says Oliveira. "He has Charcot-Marie-Tooth disease, which can cause a rapid variation in body temperature. This kid is a pianist, but his hands can suddenly get very cold and go rigid, and this happened one time when he was about to perform on stage.

"Diogo came up with the idea of pockets that would keep his hands warm. He explained his idea to us, and we put him in touch with students at Lisbon's Junior Enterprises of the Higher Technical Institute (JUNITEC), and they created removable thermal pockets. They are heated by a thermal pad that reacts to electricity, with power supplied by a battery pack.

"The motivation was to reduce discomfort caused by a rare disease, but now there are plenty of people saying that they'd like thermal pockets, even though they don't suffer from it. Investors are ready to put money into this venture, and we are working with the patient and engineering students to help them create a firm and commercialize the product."

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THE PATIENT INNOVATION PLATFORM has received many accolades since its launch, but its recognition by the medical profession as an extraordinary resource is the best reward of all.

"Patient Innovation has received many accolades, but its recognition by the medical profession is the best reward of all.

"After giving a presentation recently at the biggest surgical hospital in Lisbon," says Helena Canhão, "my colleagues there told me that in the weekly department meetings where they discuss cases, they now sometimes talk about solutions posted on the Patient Innovation platform."

Oliveira adds: "Sharing patients' ideas was, two years ago, too much for doctors. But things are changing. Crowdsourcing is happening everywhere, and there is no reason why it shouldn't happen in health care."

In the UK, Tal Golesworthy credits Patient Innovation for helping to spread the word of his invention, which won him one of the first Patient Innovation Awards in 2015. More than 120 people have received his implant. "Patient Innovation throws down the gauntlet to the medical profession," he says. "It reminds them that we are all patients and that some of us can make significant contributions to improving cost-effective health care."

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WARNING: DO NOT READ INSIDE AN ACTIVE VOLCANO

The folks at Michigan Lawsuit Abuse Watch have their hands full trying to pick the winners of their annual Wacky Warning Label contest. There were a lot of contenders, but in the end, these were the wackiest: A label on a washing machine urges patrons, "Do not put any person in this washer." For all you neat freaks out there, Super Lotto places this warning on its tickets: "Do Not Iron." No matter how many calls you make in the rain, one cell phone suggests, "Don't try to dry your phone in a microwave oven."

FROM REMOVE CHILD BEFORE FOLDING, BY BOB DORIGO JONES (WARNER)