Science AMA Series: Hi Reddit! I am Dr. Karin Hehenberger MD PhD, and Founder and CEO of Lyfebulb. I am here today to talk about how we are working on improving the quality of life for people living with chronic disease. Ask Me Anything!

KARIN.HEHENBERGER R/SCIENCE

When I was a health volunteer in the Peace Corps I routinely came across villages where in a population of ~100 there were sometimes upwards of 10% of people who had an amputated foot and rates of diabetes and hypertension ~40-50%. Trying to do awareness campaigns in these hard to reach and painfully apathetic villages felt like a Sisyphean task. What is going on in the world of diabetic research/innovation that would impact these people?

PHealthy

This is a major problem since 80% of all people living with diabetes are located in the developing world, where resources are scarce and access to care minimal. Education and different programs to raise awareness in the general population as well as to targeted groups such as relatives to those with disease are ongoing, but we need to do much more. I believe in public efforts but also in large non profits who can mobilize money and talent from the Western world. Another big player is the pharmaceutical industry - although they may not make as much money on each patient as in the US, they do have programs in the developing world where they provide drugs and even solutions for free or less money. Together with the government, these kind of public private partnerships can make huge differences in outcomes for these individuals

My boyfriend has a genetic illness that has less than 100 known cases in North America and finding anyone that can help him has been frustrating and expensive. What can done to increase the options and quality of treatment for rare conditions?

SliferTheExecProduc

It can be hard to access care and expertise for people with Orphan diseases but there are some great examples such as Alexion pharma and others where whole companies have been based on these conditions. For the individual who is suffering it is key to have a supportive family/network which your boyfriend seems to have and for that network to search for solutions in places that may not be the first
options. Searching the scientific literature may be complex, so if you have access to someone with an appropriate background to help you, that is a benefit and also if you can identify a patient group organization where some of this work may have already been done. Here you can get both information and support which is so important in times of crisis.

As you can probably guess from my username, I have a bit too much familiarity with chronic diseases. So I thought I might as well ask a few questions.

1. Do you or your organization have any involvement with Fabry’s disease or similar lysosomal storage disorders? If so, can you tell more about it?

2. Are there any general ideas or tips you can give to patients that are often home-bound or isolated due to their issues (especially gastrointestinal issues and energy issues)?

3. Do you have any general ideas or tips as to how chronically ill patients can make a living or make social connections despite their diagnoses?

4. Is there any pending legislation that we should be aware of that addresses the issue of chronic illnesses? I know that there have been a few things cropping up here and there lately, e.g. attempts at placing limitations on charitable organizations, which fortunately seems to be meeting stiff resistance.

5. Are you aware of any treatments that can help patients with energy issues secondary to a chronic disease? I was told that ADD medications can do this, but I'm not sure that's a route that too many want to go down unless they're truly desperate.

6. Is there anything in particular, or in general, that someone involved in IT may be able to do to help with chronic disease?

7. Is there anything in general that you'd like to tell people about chronic illness?

Hopefully my questions weren't too specific, too vague, or too numerous. I only found out about this AMA a few minutes ago and I wanted to post this while I had a chance, so I'm sure I'm missing some and the ones I have are probably not worded the best they could be. Thank you for your insight, and for your help with the patient communities.

sickthrowaway234

Hi - Here are my answers to your very specific and great questions! 1: Do you or your organization have any involvement with Fabry’s disease or similar lysosomal storage disorders? If so, can you tell more about it? A: We do not

2: Are there any general ideas or tips you can give to patients that are often home-bound or isolated due to their issues (especially gastrointestinal issues and energy issues)? A: Stay positive and stay involved! It is so very important to not lose energy and hope, but I know how hard it can be when you feel tired, sick and sad. Staying on a schedule helped me a lot - have small goals for yourself and try to accomplish a little more each day so that you feel progress. When I was recovering from my transplants I would try to walk a little bit longer each day and really look fwd to meals and even simple TV shows I did not watch before. Physical exercise is key to recovery and endorphins are secreted during and after, so that immediately makes you feel happier. Trying to connect with others, both healthy people and those who are struggling with similar issues can also help. Not feeling alone was important to me since being by yourself, indulging in your misery may make you paranoid and depressed.

3: Do you have any general ideas or tips as to how chronically ill patients can make a living or make social connections despite their diagnoses? A: they can become bloggers, join a patient community online or a physical one in their hometown and of course, join Lyfefulb.com! We welcome people who are living with chronic disease and we encourage them to share their stories, advice, favorite recipes and other lifestyle items with us and our growing community. As for making money, if you are an innovator, you can originate an idea, develop a product and start a company based on your experience
- fantastic way of creating wealth and health!

4: Is there any pending legislation that we should be aware of that addresses the issue of chronic illnesses? I know that there have been a few things cropping up here and there lately, e.g. attempts at placing limitations on charitable organizations, which fortunately seems to be meeting stiff resistance. A: I do not know

5: Are you aware of any treatments that can help patients with energy issues secondary to a chronic disease? I was told that ADD medications can do this, but I'm not sure that's a route that too many want to go down unless they're truly desperate. A: I would not recommend taking Ritalin for low energy secondary to chronic disease. Making sure hemoglobin values, iron levels and other electrolytes are good is a primary effort, and staying hydrated, getting enough sleep and energy as well. Beyond these basic ideas, people may still tired, and I know I did, when I struggled with type 1 diabetes, and the solution is to listen to your body and rest when needed. We have to realize we cannot do it all, and for example, when I fly overseas now, I always make sure to land a day before I need to make a presentation or have a big meeting. I need that extra day to rest and accommodate to the new time zone. For daily life it can be as simple as taking a nap or a break in the middle of a long day. Being open with your limitations is a must and any employer who values your work or a family who needs you will clearly benefit from you pacing yourself

6: Is there anything in particular, or in general, that someone involved in IT may be able to do to help with chronic disease? A: Compliance enhancement, behavior modification and making it easier to live with chronic disease all involve IT - one can even imagine games generated to help kids deal with disease online! 7: Is there anything in general that you'd like to tell people about chronic illness? A: Chronic disease never goes away - there is no break from it even if you may not feel it all the time - it affects everything you do and everything you do affects it! Therefore you need to learn how to live with it and accept that it is part of you and do the best you can. It may affect other parts of your life in a good way - your diet, exercise plans etc may need to be healthier and that is a good thing. The psychology of chronic disease is as important as the physical aspects

in all honesty, type 2 diabetes is curable via diet (ketogenic diet) and type 1 is very manageable this way - why is the medical community not recognizing or studying this further? are you interested in microbiome studies in regards to diabetes?

also - what is your stance on Lyme disease? its clear it is a chronic illness, but again, the medical community is completely backwards on this issue... its an epidemic to be honest

stackered

Hi - type 2 and type 1 are completely different diseases although the consequences of poor management of them are the same, ie death, kidney failure, blindness, amputations, impotence etc etc.

It is very clear that the early stages of Type 2 can be managed and even reversed by behavior modification such as improved diet, more exercise and weightloss, but the further it progresses, the more the pancreas gets damaged and eventually you end up with pancreatic failure and no treatment option but insulin.

In contrast, type 1 cannot be reversed by diet and it can never be completely managed with only diet changes since true type 1 means a complete loss of pancreatic betacell function and no insulin! Low carb diet and optimal weight are important in type 1 as well and those kind of modifications simplify the lives of those with t1d for sure.

I am very interested in the microbiome, in fact, I spent two years running clinical trials in a wide range of autoimmune diseases including t1d and autism using a therapy that addressed the microbiome. I
believe our western diet and lifestyle has completely messed up our gut flora and if we can reestablish the balance within the bacteria present there, we could reduce autoimmune disease, obesity and even cancer. Much more work is needed though, since it is not a one size fits all, but we probably need to biopsy the gut and modify according to the individual.

Regarding Lyme disease - it is a horrible condition especially when it becomes chronic - I have seen acute cases (including my own dad) where the disease was cleared effectively by antibiotics but I have also seen individuals who suffer from complications and chronic symptoms. Clearly a disease to take seriously and a modern time syphilis is that it resembles other diseases and thus goes undiagnosed in many cases for months to years!

Can you talk about some good examples of patient entrepreneurs?

orangepanda2

We have some great ones on our website! http://lyfebulb.com/lyfebulbs-entrepreneur-circle/ For example - John Sjolund, who is a Type 1 diabetic and has developed a cap for all insulin pens that will remind you of when you last dosed insulin and thus avoid extra shots or missing a dose. Another example is Jen Ross, another type 1, who developed a sugar free, naturally sweetened cocktail mixer, Be-Mixed that can be used in alcohol as well as alcohol-free cocktails. A third one is Scott Smith, whose Father died of type 1 and Scott has developed a non-invasive glucose monitoring device...

On the topic of diabetes, specifically type 1, I recently became aware that you can now have insulin pump/blood glucose monitors that will send the information to your phone viewable by app. This avoids the need for constant finger pricks etc.

How do you feel this type of technology has/will fare with those affected by this disease? Have people taken a liking to this new method of monitoring?

newman1080

Yes - continuous glucose monitoring and continuous insulin delivery are two modern technologies that have truly revolutionized diabetes care. Not only do they make life more convenient and removes the pain of pricking your finger up to ten times daily and giving yourself injections, but these technologies enable people to live a freer life and improve their metabolic control. In the future, we hope that the links between these devices will be seamless and safe, so that the human involvement is small and thus the person with diabetes does not have to think about their disease all the time!

I saw on your TEDX Talk that you have Type 1 Diabetes. My nephew was just diagnosed with Type 1. What is it like being born with a chronic illness and how do you manage it? Has it helped you in any motivational way?

blueeyes115

Well, I was diagnosed at 16 and it really made me focus on medicine, finding cures and better therapies for people like myself and to dedicate my life to science. In some ways it was a good thing, since I live a healthy and very productive life with diabetes and it has forced me to learn as much as possible about the many ways I can stay healthy despite my condition. However, I cannot pretend to live diabetes - it robbed me of my control and my sense of freedom as a teenager and I will never completely get rid of the feeling of being trapped into a body that failed me. I believe everyone who is struggling with a chronic disease feels the same way - there is no break and no vacation from the
situation and even if we make the best of it, we feel anger and resentment toward the disease. The optimal way to deal with it I believe is to become engaged and try to help others and importantly allow others to help you!!

In your opinion, do we have the drugs/technologies in place to well address the needs of the diabetic population?

Can you comment on where or what shortfalls there may be with available treatments for diabetes today?

What is the regulatory/FDA landscape like today, particularly in the US, for up and coming drugs/diagnostics/devices/etc that seek to improve management and treatment of diabetes?

Can you elaborate more on your Entrepreneur Circle? What is your confidence level that the group can make a difference in the diabetic population? If so, how?

What are the stumbling blocks and hiccups to getting new diabetes drugs/technologies to market?

ValerieVirata

We have good drugs and we have good devices but we need better! For example - 1: we need insulins that are delivered to the liver first and thus replicate the endogenous insulin secretion. 2: we need automated insulin delivery that is linked to glucose levels so that we do not experience glucose ups and downs (variability)

The FDA is very strict for diabetes drugs/devices and not at all as aggressive as they are for cancer and HIV/hepatitis drugs - this is a shame since diabetes kills and mutilates but since we can manage the disease with insulin, the FDA does not see the same urgency and have the same risk/reward perception as they do for other diseases with more acute situations.

Our EC is unique in that these individuals truly know what it is like to live with diabetes and their inventions are driven by that passion and experience - I am personally convinced that they will completely change the way we treat diabetes in industries ranging from med device/drugs and consumer products!

Huge clinical trials are needed for new diabetes drugs which requires big dollars and then followed by costly sales operations and marketing - those are the hurdles in diabetes drugs and this is what limits some of the start-ups in the space

Thank you for your AMA. I am sorry to hear about your diagnosis, but very happy to hear about your story as it is very inspirational. What was it like doing a TEDx talk? I also think growing a community like this is great idea for patients and family/friends alike. What are some things that members can do in the community?

Dhealth1

Thank you!! It was fabulous to give a TEDX talk - I loved every moment of it!

Our members can communicate with each other, they can learn from each other and from our experts and from reading our stories. They will be able to get inspired by our innovators and in the future learn about products that are generated by patient entrepreneurs and even buy these products or learn where to find them. Importantly - they will also be able to share advice with others, develop friendships and mentoring roles. We want to "turn the lyfe" back on for people who have historically been seen as victims and we want to empower them to do great things!
Are there any proven strategies for improving quality of life for people with chronic disease? How do you see medical care improving for chronic conditions in the future?

p1percub

That is a very difficult question to answer - there are a number of products out there that have shown medical benefits - such as improving glucose control in diabetes, lowering blood pressure in hypertension, improving stiffness and pain in RA etc etc, so all approved proprietary drugs have those requirements since they have been FDA approved. However, some QOL improvements are not part of regulatory endpoints and thus are not measured in clinical trials! this is where patients and organizations such as Lyfebulb come in - we focus solely on this and we identify products that do just that - help in small and large ways with daily life. It is becoming clear that medical doctors and regulatory authorities are placing more emphasis on QOL, which I think will improve medical care in the future.

Hey Dr. Hehenberger, first a heartfelt and sincere thank you for all that you do and helping improve lives like mine. I found out I have Type One at the age of 28 in the winter of last year and honestly the hardest part for me has been the general perception of the disease. Before I was diagnosed I had no idea either, but I find when family or friends or co-workers find out I have Diabetes the typical response is "I don't remember you eating particularly bad" or "You're not that heavy" or worst and scariest "I heard that diabetics are prone to passing out, so if I happen to find you unconscious I just give you a big shot of your insulin". I've only had it nine months, but I've had three lows so bad I basically had seizures and have already had the beginnings of retinopathy. All this is to say, it is an extremely difficult and ruthless disease and the general population seems to perceive as a joke, so I am wondering if you know of/ are working on ways to bring more understanding and awareness to the general public? Not saying this AMA right now isn't doing that exact thing, but I feel like this will mostly get the attention of people who live with or around a chronic illness.

nuckingfuts73

Great point and that is one of the targets for Lyfebulb - to improve the general knowledge and not just in the community where we already know that type 1 and type 2 are different and that giving a person with low sugar an insulin shot would kill them!! I feel for you as I have experienced very similar things and I still remember being asked by a top executive at one of the largest pharma companies in the world why I was not "fat" since I was diabetic... We are trying to be out speaking to general audiences, my TEDX talk being an example but we need to reach a consumer even POP culture community as well - we are working on it and I am determined to increase our reach and our importance in mainstream media by being interesting enough, attractive and innovative enough to gain attention from people who otherwise would only focus on fashion, reality shows and food!

Hi Karin! I'm an electrical engineer focusing on the artificial pancreas in the hospital space. My question to you as a Type 1 is: Do you think seasoned Type 1's will ever trust a machine/control algorithm to do dosing? What about nurses and MDs? What can we, as researchers, do to promote our devices, aside from simply having great results in clinical and simulation work?

t40

Hi, thanks for your question - people with type 1 would like nothing better than to stop having to think about their disease so yes - if the algos work and the devices have gone through extensive clinical testing they would be met with enthusiasm! I have a pancreas transplant myself, so I trust medicine
and science, and look fwd to the time when everyone can stop injecting, measuring and WORRYING about not waking up due to a low, or feeling terrible and getting complications such as blindness and kidney disease because of the highs.

However, it is not easy to replace biology and the algos need to take a lot into account, and we need to have more than just insulin in the pumps since glucagon and amylin and maybe other peptides are needed to achieve optimal metabolic balance.

I applaud your efforts and I really hope we will get to a solution soon!

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Hi! While we were talking this happened! The FDA approved the first artificial pancreas by Medtronic - a pump that corrects high sugars and shuts down when the sugars are low! It is approved for people with type 1 above the age of 14:

According to the FDA, the device measures blood sugar every five minutes, then responds by sending insulin into the body, or holding steady. Diabetics can also manually request insulin around mealtimes.

A clinical trial of the MiniMed 670G involving 123 people with type 1 diabetes had no serious adverse events, though the FDA notes that “risks may include hypoglycemia, hyperglycemia, as well as skin irritation or redness around the device’s infusion patch.”

While the device is approved as of today, Medtronic will do additional testing to see how well it works in real-life situations. The company is also conducting additional trials to see if it can be used in children 7 to 14 years old.


Do you know anyone at Novo Nordisk that would do an AMA?

FuckRevs

I would not be able to speak for Novo

What are your thoughts about situations like that of Paralympic athlete Marieke Vervoort of Belgium? She has a spinal disease causing her so much pain she often doesn't sleep more than 10 minutes a night. Now that the Rio Paralympics, her last competition, are over, she might come to a point where she'll resort to euthanasia to peacefully finish her life. http://www.dailymail.co.uk/news/article-3775473/Belgian-Paralympian-Marieke-Vervoort-considers-euthanasia.html

heywoodu

I have no comments - each individual must choose their own path

What other chronic diseases are being discussed on the platform aside from Type 1 Diabetes?
We have been focusing on diabetes but we feature stories from people living with cancer, MS, Crohn's and ulcerative colitis as well as Lyme disease. Theoretically all chronic disease but clearly a focus on autoimmunity and cancer.