

## Highlights from the BEAt-DKD Symposium on Precision Medicine in Diabetic Kidney Disease

The BEAt-DKD consortium ([www.beat-dkd.eu](http://www.beat-dkd.eu)) is a public private partnership of 20 academic institutions and 8 biopharmaceutical companies supported by Innovative Medicines Initiative (IMI). BEAt-DKD's goal is to improve prevention and treatment of Diabetic Kidney Disease through precision medicine. Ways to reach this goal are to identify novel biomarkers, estimate individual renal and cardiovascular risk, and improve stratification of patients.

BEAt-DKD is organized in six Work Packages, out of them first four (WP1-4) concentrate on “discovery” and last two (WP5-6) concern “validation, integration and translation”. Specifically, Work Package 6 focuses on applying knowledge generated from other WPs into precision medicine approaches into clinical practice by developing an optimal clinical study design and integration in the regulatory process of drug registration.

Implementing available and newly developed biomarker scores to improve development of new treatments in DKD requires close cooperation of diverse diabetes stakeholder groups. WP6 is therefore organizing meetings with various diabetes stakeholder groups (e.g. patients, physicians, regulators, health technology assessors, industry, and academia). These meetings aim to identify obstacles and brainstorm solutions for precision medicine in DKD.



One such meeting was the Symposium on Precision Medicine in Diabetic Kidney Disease, held on 3-4 April 2019. Seventy-one participants representing a number of different diabetes stakeholder groups met in Amsterdam, The Netherlands for a 2-day workshop. The symposium included plenary talks from distinguished speakers, breakouts for discussions, and social dinner to facilitate interaction. At the end of symposium, obstacles and solutions were identified on how to implement personalized medicine in diabetes care. A White Paper will be written from the symposium.



## Participant Spotlight: Mark Smith Patient Advocate for Kidney Care UK

### Tell us about yourself

I am 47 and a stay at home parent as well as a double transplant recipient. I am an inspirational speaker and charity fundraiser. I have raised around £15,000 for charity. I am also a bravery award winner, member of the Patient Advisory Group for Kidney Care UK and I am on the organ donation committee where I live in Harrogate in the UK. I am also an organ donation advocate and have done much in the media promoting OD including live TV and Radio. When I am not speaking I am at home with my 2 children, Emily 8 and Ellie 4. My hobbies include amateur theatre (23 years), reading and distance walking.

### You're a DKD patient. Can you tell us a little bit about your experience with the disease?

I was diagnosed with Diabetes when I was 14 years old (I came out of hospital on my 15th birthday). I then spent 25 years as a Diabetic and ended up with all sorts of health issues with my eyes, bladder and stomach, plus a few other bits and pieces. I was diagnosed with DKD in 2007 and was told I would likely need a transplant in 2008. They discovered the DKD through a university study rather than me feeling unwell. In Dec 2008 I was listed for the transplant and then in July 2009 I had the double transplant (this July is my 10 year anniversary). Today although I have days where I feel unwell I try to own my disease rather than letting me own me, hence all the walking, charity work, media and inspirational speaking. I use all the bad things that have happened to me to tell a story to encourage and inspire other people. The biggest issue is infection and I had a nasty one earlier this year which took some getting over it (but I am better now!!)



### We invited you to a previous BEAt-DKD focus group and now this symposium, where we've tried to come up with a plan for implementing personalized medicine in diabetes care. Do you think your current care has been personalized? What are specific areas for you in the health care process that can become more personalized?

It has been an honour to be part of the initial focus group and the symposium and it certainly resonates with my own care. I feel as a transplant recipient that in many ways my care has an element of personalised to it. For transplant medication cannot be broadly based as routine for everybody. So in many ways I am already receiving personalised care. I think however that from the outset, even people post transplant are given a standardised spectrum of medication, immune suppression, steroids etc which then gets altered over time to a more bespoke regime. If personalised medicine can look at the individual needs from the outset, based on those biomarkers then perhaps there can be a more tailored approach from the start and the propensity of failed transplant may see a drop. Another answer to this is when I was Diabetic it was generally thought that an immediate acting insulin could be taken just prior to a meal. But they never figured out with me that my body would store the insulin for me. I would then have my meal, my blood sugars would go up and then crash down with an extreme low blood sugar happening. This was never explored in any depth so it was just assumed I was not looking after myself properly. Maybe if PM was in place they could have tailored this treatment plan accordingly and I may not have needed the transplant itself (though I really don't mind not having to do injections of course !!)

### What is one thing new that you learned during the symposium?

One thing that I learnt during the symposium is how there can really be a common cause amongst different stakeholders and compromises can be reached with them. I also learnt the depth of medical knowledge out there is staggering, especially when people were talking about Diabetes and pathways in the human body that are not consistent with everybody.

### If we lived in a perfect world, what is the one thing you most wish for regarding your health care?

If we lived in a perfect world, the one thing I would wish for in healthcare would be immediate access to HCP's or Dr's - even through video calls, to discuss medical conditions, worries etc. So you may not even have to go to a physical hospital for appointments.