Gitelman/Bartter syndrome support day

Programme

11.00  Registration and coffee
11.30  Welcome and introduction  Prof F Karet
11.40  Gitelman and Bartter syndromes: what they are about  Dr D Bockenhauer
12.00  Patient/parent voices x3 (Clifford, Charlesworth, Miller)
12.30  Why does my treatment taste so awful?  Prof R Unwin
12.50  Q/A  All
13.15  lunch
14.10  Food choices: maximizing potassium and magnesium  Ms C Parslow
14.30  Breakout groups
15.00  Tea and planning  All
15.30  end

Supported by

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Held at the Academy of Medical Sciences
41 Portland Place
London W1
on Saturday June 11th 2011.
Sue Charlesworth, Preston, Lancs
"I cannot begin to tell you what this event meant to me personally and also the members of my family. My husband and I so enjoyed the day and found the experience invaluable. I feel I have literally battled over the years for my symptoms to be understood. My family have known and supported the real me when I have returned from work shattered each night. If it hadn't been for them and my brilliant GP I would never have got through everything. I really wanted to say that on Saturday, but would probably have got emotional which wouldn't have been helpful to anyone! As it was the actual experience of "telling my story" to the others was amazingly cathartic. So many of the other patients and their families came up to me afterwards to say that it had struck a chord with them - it had to be worth my knees knocking and the terrible fear beforehand!

It was wonderful to meet patients and their families who had been through the same or similar experiences. No longer will I feel I am on my own with this. Instead I will be proud that I have been diagnosed and am getting on with everyday life of family and home. The best news I have to tell you is that my brother actually went voluntarily and had blood tests done on Tuesday (after 14 years your support day motivated him to do that!)

So once again thank you for your understanding and foresight that this support day was much needed and wanted. As I said on the day, if I can be of any help I will certainly try my best. In the meantime, I will try and speak to some of my colleagues on the Associate Parliamentary Limb Loss Group (APLLG) to see if we can draw on any of their experience of moving in the area of politics and health.

I explained in our group sessions in the afternoon that when I returned to work after my 5 months sickness absence in 2007/8, I found our Occupational Health Department Doctor extremely supportive. He felt that Gitelman Syndrome should be recognized under DDA as an illness that "substantially effected the ability to carry out day-to-day to tasks". I think that this may be something we could explore too.

Looking forward to being involved in the future of this very much needed support group."
Helen Robins, Fringford, Oxfordshire

"Although we sat in a room of strangers, the connection we felt to everyone there was immediate and emotional. As a parent, I felt that at last my daughter could take possession of her condition as an adult in the company of others and that we, as her parents, were the no longer her sole support in what had always been a very lonely journey for her. The day ended with the possibility of a forum so that anyone diagnosed with either Bartter's or Gitlemans' (and their parents, relatives and friends) might find that connection more quickly and not feel they are quite so alone. This would be an invaluable outcome."

Peter Park, Huntingdon, Cambs

"On arrival at the excellent Academy of Medical Sciences conference facility I looked around anxiously to see what a fellow Gitelmans or Bartters Syndrome patient looked like. I quickly realized that they look like us! - a true cross section of the population, and outwardly no different than anyone else. Inside those present on 11 June there was a special 'vibe' and intensity of desire to learn more from the experts and share our mutual experience. Refreshing was the dedication of Professor Karet and her colleagues, who donated their own time, to equally learn from us. The dynamism in that room was palpable in fostering a day we will not soon forget, with huge thanks to the kind sponsorship of the British Kidney Patients Association that made it possible. To be associated with the BKPA, and that amazing group's embracing of our medical conditions as their own is a true stride forward. I am excited as we move onward."

Kevin and Julia Plummer, Nuneaton, Warks

"We lost our daughter Alyson in 2005 due to a lack of managed care of her Gitelman's condition, predominantly due to a severe lack of knowledge of the condition by many general medical professionals. Since that tragic time we have tirelessly campaigned for 2 things.

1). More awareness of these rare conditions, and more accurate information being made available to medical staff. And

2). The requirement of any sufferer of this and any rare condition, to be referred to expert, to a) allow the sufferer the best treatment and information available and b) allow the experts to gain more experience and therefore improve knowledge. The formation of the support group is so important as the thing Alyson wanted most of all, was to be able to contact others with her condition and share experiences, symptoms, knowledge and most of all not to feel alone."
Luncinda Garner, Brighton, E Sussex.

"When I was told about the support day, I was very excited. I could not wait to meet individuals who were also living life with Gitelmans' and Bartters' syndrome. I like others, have never met any person with the same condition. Listening to the speakers discussing the impact of the condition, on their lives, made me feel at times I was looking at my own reflection. In the twenty years I have been dealing with this condition, I was provided comfort to know I was not alone.

Having family and friends surround the room with their experiences made the day, very emotional. It was not just a day for the patients to feel supported with others who suffered from the same condition; it was a day for family and friends to have an opportunity to discuss with other family members, the highs and lows of caring for their loved ones.

Before this support day, I felt alone and at times abnormal to the rest of my family and friends. It was a condition I was disappointed to have, especially when dealing with hospital admissions and the battle in having to explain the condition to the doctors and nurses; who never heard of such a rare disease. However after attending this support day, I am now proud and excited to have Gitelms and to no longer feel alone. In fact to be one patient of a very small minority of extraordinary people; supported by a very special professor Karet and her team”.

Lynn Bean, Norwich, Norfolk

"Being a teenager growing up with Gitelman's is a hard thing to describe, you feel afraid to tell people in fear that they will automatically judge you and often think that you are alone with the condition. However when i saw that letter about the support day i felt relieved and nervous. I was excited about meeting new people but having coped with Gitelman's on my own for so long i couldn't comprehend that there were people in the same situation as me. However as soon as i walked through the door, people were waiting to share their experiences, stories and advice, that they made me feel so welcome. I realised that we were all in the same boat and all needed the support day to breath a sign of relief and think...'actually i am not alone'. I managed to meet people around the same age group as me, which allowed me to discuss how Gitelman's effected our school life, jobs and everyday challenges. All the speakers knew what they were talking about with the ability for questions to be answered in a way that everyone could understand. I throughly enjoyed the day and am now proud of my condition instead of seeing it as a set back. Emily"

Jane Hawkridge and family, Hertford

"Just to thank you all for organizing the Gitleman/Bartter support day. Thank you for giving your time and medical knowledge. I’m sure we all learnt something new from this meeting. And knowing you are not imagining this illness and symptoms is a comfort. We must all also remember if it were not for people like yourselves at the NHS hospitals we may not be as we are today living our lives.”