

Pompe Online Meeting 001: COVID-19

Hosted and facilitated by Allan Muir for the Pompe Support Network
Friday 27th March 2020

Meeting notes by Allan Muir, Chair, Pompe Support Network

Participants

The meeting was small, with 14 people on the call and one person who failed to connect. Two industry representatives joined but left early, feeling that their presence was inappropriate. Three participants were from the USA and one from France. We also welcomed an AGSD-UK observer who was interested in using the Zoom facility for a wider audience, but who also played an active part in discussions.

Summary

The event was the first online meeting organised for the UK Pompe Community using Zoom conferencing, so it had a few teething problems. I had thought that participants could join through their web-browser, but it seems that all participants had to download the Zoom mobile app or computer application. As Zoom is becoming the industry standard for online meetings, this isn't a problem for many people.

The meeting flowed well with little prompting from the facilitator (AM) and all discussion points prepared in advance (below) were covered. I've added my comments in [blue](#).

Participants enjoyed the format of the meeting and suggested that they should become a regular event throughout the COVID-19 epidemic. I suggested that these might be enhanced by inviting specialists to give short presentations with Q&A followed by free discussion.

There was general agreement that we should begin a series of meetings. So, we will start to plan a "Zoom into Pompe" series for the coming weeks.



Allan Muir
Pompe Support Network

Discussion points

Social distancing, Self-isolating and Shielding – definitions

- Social Distancing – everyone
- Enhanced Social distancing – Paediatric guidelines
- Shielding – for extremely vulnerable children and adults
- Self-isolating – where contact with COVID-19 had occurred

Everyone was happy that they understood the difference between these guidelines.

Mixed messaging

- NHS, Specialist teams, Homecare staff, LSD Collaborative guidance.

Not all had received letters from, or talked with, their treating consultant. There was much discussion about this, but people seemed generally happy with their decisions on screening and social distancing.

Homecare issues

- Shielding is incompatible with nurse support
- Semi-independence and full independence – limited training could be available by homecare companies.

No participant was independent of nursing care, and so they have all had to consider drug holidays. Some are continuing with treatment and others have discussed their vulnerability with the LSD consultant and have decided to voluntarily stop treatment. Not all had been contacted by their treating centre. One was offered monthly infusions to try to reduce the risk of contracting COVID-19.

Experience was shared regarding drug holidays. Some years ago, one participant stopped ERT for three months during pregnancy. She felt that she had lost very little muscle function after restarting therapy. Another lady continued to decline whilst receiving Myozyme and so she voluntarily stopped and has not received therapy for five years; her disease progression is very slow, though noticeable. Such stories may bring a small amount of comfort to others considering a pause in their treatment. A major concern in the group was how long the pause might be.

Government help for vulnerable individuals – Website

Those who required it were aware of it. Apparently, Tesco are working with the government to offer delivery slots for vulnerable individuals.

Alternative strategies during drug holidays - diet and exercise

- Frailty increases – more at risk – online course
- Breathing – Respiratory training
- Keep active? – seated exercises
- Dietary changes

I raised this topic and discussed dietary and exercise advice that was common before Myozyme was available. High protein diets we once recommended to reduce glycogen storage and to provide amino acids for muscle building and repair, exercise was recommended to reduce the amount of stored glycogen. More recent experience with ketogenic diets has been interesting, but more studies are needed. No participant was actively adopting alternative strategies to slow disease progression, but the group were interested in the idea of future online meetings to discuss such topics.

General health

- Boosting immunity
 - Vitamin supplements
 - Healthy diet
 - Keep active

I raised this because very little is publicised about boosting the immune system. Our website COVID-19 page contains a link to [How to boost your immune system](#).

Maintaining sanity during isolation

- Anxiety
- Mindfulness – online courses
- First Aid to Worry
- Online Choir?

There was little interest in singing as an online choir, but mindfulness was discussed as a useful tool to aid mental wellbeing. Wayne recommended a small book "[Mindfulness Plain & Simple](#)" by [Oli Doyle](#) as a great help, providing thought exercises for mindfulness.

Mindfulness courses were discussed, many online and mobile apps are currently being offered for free. For example:

- [Calm](#)
- [Headspace](#)
- [Oxford Mindfulness Centre](#)