Q&A with Shahin Moledina, Lead of the Children's Pulmonary Hypertension Service and Iain Armstrong, Chair of the PHA UK

7th April 2020

Iain: Good afternoon Shahin. Thanks for spending some time doing this infocast because I know there are lots of anxieties from parents of children with PH around the coronavirus issue. Would you just like to introduce yourself to people who might not know your full background and clinical role?

Shahin: Thank you for organising these infocasts, they're very helpful. For people who I haven't been fortunate enough to meet yet, I'm Shahin Moledina, the lead for the children's pulmonary hypertension service for the UK. I'll have met most of you – our service is mostly Great Ormond Street Hospital, but we work very closely with centres around the whole UK.

Iain: How long have you been at GOSH as a lead?

Shahin: It's been around eight years, long enough to have met most people and before that I did some research at GOSH and did junior doctor training.

Iain: So, let's focus on the here and now. As far as the children's service in the UK is concerned, how do you feel your service has responded to the current situation, especially regarding the collaboration within the PH service in the UK?

Shahin: This has been a shock to everybody's system, but one thing about the PH community in the UK and globally is that it's a pretty tight-knit community. We've been on conference calls between all of the adult PH centres from very early on in the COVID-19 process to plan how we're going to deliver care to our patients when things change and to have a coordinated response, learn from each other and share best practice. We've been in contact with the PHA UK, commissioners at NHS England and informally with our colleagues around the world so it's been a really coordinated response which means that everybody can pick up ideas from each other.

Iain: That's very reassuring to our listeners. I know that in the UK there's definitely a frequent weekly telephone call but even between that there are emails, so sharing best practice is absolutely crucial and I think that collaboration is the way forward. I'm absolutely certain that there'll be much to learn on the other side of this pandemic and that bodes well for the future. Just on a more practical basis, what's happening to people who've got children at GOSH or one of the outreach centres around managing appointments?

Shahin: Just like all other services we've had to change and there are two main things which have driven that. The main one is that we really don't want to expose children and their families to potential infection if we can avoid it. We want to try and deliver their pulmonary hypertension care as safely as possible without bringing them to hospital unnecessarily.

I think a lot of people will realise that hospitals have also had to focus a lot of resource and energy in coronavirus care and cut back on inpatients. So, what we've done is very similar to what the adult PH service has done and it's been very helpful to do this in a coordinated way. We've cut back face-to-face clinics, but we do have the capacity to do them when it's absolutely necessary. We have a small number of clinical appointments at Great Ormond Street and that's in a separate building called ZTR so there are no inpatients to minimise risk.

I've also been in communication with our shared care centres and they are also maintaining the capacity to see a small number of patients face-to-face where it's needed. For most patients what we're doing is offering non face-to-face consultations and that's video, which I was just doing today, and they've been going really well. For people who don't have a webcam or can't do video for some reason we're doing telephone consultations.

Iain: So the care is ongoing, but it's just being delivered at this time in a different way?

Shahin: Yes, we've been doing it for a couple of weeks like this and it's been working very well. I think patients have appreciated doing it this way and I suspect we'll probably do a fair few like this in future.

Iain: It's a case of learning from the present experience and what the good is in all of this, and how to manage individuals better particularly from a distance point of view once you know the situation, so there's definitely some good to come out of this.

It's been very clear that people with PH should shield themselves, but one of the questions we're asked through our website and social media is whether that is the same for children with PH? What's the advice there?

Shahin: In short, that's what we're advising. We're all in a learning curve with this – so far fortunately children seem to be less severely affected than adults but we don't want to be complacent about this and we know that children with pulmonary hypertension can become unwell with influenza, and that's why we recommend an influenza vaccination. So to be consistent and to avoid risk we're recommending isolation and we're working on sending information out to patients to recommend that. We've been working with NHS England to make sure that PH for adults and children appears on the list of extremely vulnerable conditions, so we are recommending shielding.

Iain: Have you changed any of the advice on regular blood testing that might be required for individuals who take certain drugs?

Shahin: We've thought long and hard about this and it's slightly more complicated in children in that some of the information about the safety of some of these drugs is less comprehensive than it is in adults. So it's hard to know from the literature, especially for the younger children, exactly what the risk of liver problems is with some of the drugs. We've always recommended monthly testing even for patients who have been very stable.

We've gone through the list of all our patients who are on these drugs, for example the endothelin receptor, to make sure we've got up-to-date blood results up to at least February. For the vast majority of patients we've said that on balance, it's better to shield and delay the blood test until we come out of the other side, and we've picked out a few individuals who we think might be slightly higher risk because of their background medical condition. We're contacting those people directly and making alternative arrangements.

Iain: If a child with PH who's under your care shows symptoms of COVID-19, what's the advice to parents? What would you want them to do if they were concerned that their child may be showing signs of COVID-19?

Shahin: Obviously people will be hyper-vigilant for these things. The first thing to do, just like everybody else, is to access the NHS advice through the website or by phoning 111 and take that advice. We would also be very grateful if patients could let us know by telephone or email so we can keep track on their progress and make sure things are going in the right direction. But the first thing to do is contact the local services, and that may also include phoning the GP, but I think 111 is the first port of call. Also, there is up-to-date and very good advice on the PHA UK website.

Iain: This sounds very similar to the whole population, but you're asking patients to let yourselves know if they are showing symptoms or test positive. I think it's about using the safest avenue to get things sorted – it is safer to follow the government guidelines and use local services first rather than waiting for something else to happen and that's why the whole structure has been set up this way.

Shahin: That's exactly right – they'll be manned 24/7, they'll have up-to-date advice and they'll know what local services are available at any one time. We want to join in the patient's care afterwards, but we don't want to delay them getting the right care at the right time.

Iain: If a child became very unwell with COVID-19 and was admitted to hospital locally, what would happen there? Do you expect that local team to contact yourselves or would you want the parents to let you know?

Shahin: This is very much like any other time if one of our patients becomes sick and ends up needing to be admitted, except the hospital they are admitted to will be under a bit more stress. We would hope that the local hospital would contact us directly, and generally they do, but it's also really helpful if parents communicate with us so that we can make sure that the local hospital has got all the background information.

I think it's always helpful if families take their up-to-date medical records, such as their clinic letter with their list of medications on it. Last year we swapped over to an electronic patient record and it's got a facility on it called 'My GOSH' which any patient can register for, and most of our patients have already registered for. There they can access their clinic letter, drugs and some blood results from their devices at home and share them with the hospital that they're admitted to.

Iain: So, in essence it's about having this information ready if you become unwell just in case.

Shahin: Absolutely – it's always helpful to have that and I think most people know that. It also saves patients a lot of stress when they're being asked about their medical history in the heat of the moment.

Iain: Having that checklist is absolutely crucial, not just in the present climate but it's a really good way to be pro-active in their care of children and adults with PH.

What would your key message be to parents and children in regards to their PH and the COVID-19 situation?

Shahin: It's probably a message to them and all of us in that this is an unprecedented time and we're all worried and immersed in it. Watching the news updates also causes a lot of worry and being in the house alone makes you feel isolated. My key message is that you're not alone – there's a whole army of people behind you ready to help. Feel free to reach out for help as and when you need it – we'll be here just the same as always even if it's virtually. The PHA UK is there, so people shouldn't feel as scared and alone as perhaps they do.

I also want to take a positive out of it – we will come through it and hopefully we'll come through it stronger and better and we'll have learnt lessons and new ways of doing things. In the longer term, we'll hopefully have improved our services.

Iain: That is a positive and I think one of the things that is really showing in the UK is the way our PH service is set up is the envy of the world. We've got a structure which means we can get through this together. It is a team effort and a huge part of that team is the individual with PH. I'm absolutely certain that we'll have an even better pulmonary hypertension service than we had before we went into it. We at the PHA UK are really grateful for your time – we may get back in touch with you in future and it would certainly be good to catch up on the other side of this.