

# **Attendance at 2018 International Pulmonary Hypertension Conference & Scientific Sessions, Orlando, USA June 28 – July 1**

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I was privileged to have been invited to attend the above conference which I found informative, inspiring & encouraging for the future. The meeting was titled

## **‘PHinding your hope’**

There were many breakout sessions and workshops to attend. The following are some brief notes I took while attending these sessions:

### **SESSION 1: Tips & tricks for conserving your energy:**

This session was conducted by two adults with PH and are both support group leaders. The opening comments were ‘Life goes on after diagnosis’. PH patients and caregivers need to get the most out of each day by conserving energy, making “me time” and simplifying daily tasks’

#### **Objectives:**

- Learn how to cope with constant demands on your mind and body while living with a chronic disease
- Gain an understanding of the ways you exert emotional, mental & physical energy during everyday activities
- Learn how to make life easier

#### **Key Messages:**

- A person with PH who runs a busy family home only needs 3 things..... a Maid, a Chef and a Chauffeur !!
- There are various levels of activity:
  - Level 1-2 Brushing your teeth – general conversation
  - Level 2-3 Getting dressed, cooking
  - Level 3-4 Showering, washing dishes
  - Level 4-5 Changing the bed linen

It is estimated that the energy used while showering or washing dishes is the equivalent to walking 3 miles per hour and changing the bed linen is the equivalent to walking at 4 miles per hour

- The best way to conserve energy is learning to say “no” Incorporate rest into your schedule – plan for rest, occasionally give yourself a “day off”
- Use oxygen and mobility devices as prescribed
- Share household chores
- Sit when possible while doing daily chores or in the shower
- Get comfortable with computers by shopping online, paying bills on line and keeping in touch with friends through social media
- If you like to go to the supermarket – shop at off peak times
- Avoid bending over at the waist towards the floor; use long-handled devices such as a reacher/grabber
- When taking shower – keep the room ventilated and don’t let steam build up. The shower should be warm, not hot or overly long.
- Alternate motions that use the arms. Avoid holding your arms overhead for long periods of time.
- Push heavy items along a counter versus lifting and carrying
- Keep frequently used items between your waist and shoulder level
- Plan ahead to avoid rushing (eg if going somewhere early in the morning – shower the night before)
- Don’t be afraid to ask for help, use handicap parking facilities. Always remember – ‘There’s no shame in my game !’
- Know your limitations but still try to maintain your independence
- Finally learn to accept your limitations – this will conserve your emotional energy

## **SESSION 2: Communicating in a PH Emergency: Am I prepared?**

This session was facilitated by an adult with PH who is a support group leader who told of her medical emergency experience – when she wasn’t prepared.

### **Objectives:**

- Define PH emergency & understand why immediate action is critical
- Learn how to be prepared & proactive in a PH emergency
- Learn how to respond to a PH emergency with confidence as your own advocate

**Medical emergency experienced by speaker:** This session was facilitated by Dawn Jones who related her experience to the audience. One hot summer’s day she was at the beach with her daughter and grandchildren. She decided to paddle in the water and had her pump in her hand. Unfortunately she twisted her ankle on a stone and fell. The pump became submerged in water and although she immediately got out of the water and tried to dry the pump – the

alarm started to ring and the pump failed. Her daughter rushed her to the nearby hospital. Dawn tried to explain PH to the doctor on call. She was hysterical trying to explain how important that her IV PH medication cannot be stopped – the doctor tried to sedate her and took her phone from her (she was trying to call her family doctor). There was a very long story about security removing her daughter from the hospital etc & Dawn jumping off the trolley and being man handled by security when .....thankfully a nurse in the Emergency Room heard the commotion and asked what was going on – she had experience of dealing with PH before and advised the team on the appropriate procedures. Dawn received IV treatment and thankfully made a full recovery.

### **Preparing for a PH Emergency:**

- In the past patients were told to always have their documents with them, now everything can be stored on a mobile phone
- Create a file of all your medical details
- Save your doctor's contact details on your phone
- Scan your latest prescription and relevant documents
- For continuous infusion therapy, know who to contact for pump-related issues & have emergency contact details
- When leaving home – always bring a spare pump and extra medication with you
- Should your phone be locked - allow the facility to call ICE (in case of emergency). Ensure the person you propose knows your condition and can unlock your phone
- Educate your family, friends and others on how to respond if you have a PH emergency. You could have emergency drills for your home, like a fire drill.
- It is vitally important that whoever your emergency contact is should be fully aware of PH including list of medications and your PH care team's contact information.

**Conclusion:** The above story was a very serious incident and Dawn was traumatised from the experience. However when she related the situation to her PH nurse, they decided between them that they would not write letters of criticism to the hospital and media etc but would be pro-active. The PH nurse wrote to the Director of Nursing in the Hospital and praised the intervention of the nurse who came to Dawn's rescue. She also wrote to the Medical Director advising him of the incident and proposed that she would arrange an education session for the staff in the ER. She obtained sponsorship and organised an intensive educational session for the staff to ensure a situation like this will never happen again.

### **SESSION 3: PHinding your hope through fundraising**

Like all PH associations, the PHA in the US relies heavily on support from donors to support it's mission. The PHA must raise \$9m every year to support the running of the Association

**Objectives:** To encourage volunteers to raise money for the PHA

**Suggestions:** Events organised are very similar to those we organise in Europe – eg.,

- Fun runs, Walks organised by members of the 240 support groups throughout the country
- Workplace giving
- Major ‘once-off’ donations.
- Online donations
- Making a planned gift through a will or bequests

**List of future events advertised:**

It was impressive to see how all of the various support groups across the country came together and created a calendar of future fundraising events

## **SESSION 4: Living a new normal**

**Session description:**

When diagnosed with PH, you experience so many changes that you may feel like you’re no longer living your normal life. Three adult PH patients shared strategies on how to cope with the sadness that come with losing aspects of your old life as well as adjusting to living a new life and accepting the new you !

**Objectives:**

- Understand how even if PH brings on a new normal, you are in control of defining what that normal can look like
- Understand that a new normal is possible and can be wonderful
- Learn how to find creative and safe ways to do what you enjoy

**Key Messages**

- It’s OK if PH rocks your world at first, but the truth is that this disease does not define YOU
- Creating a new normal means figuring out what you can and cannot do anymore – how you can still do things you love, even with PH limitations
- You have a choice whether you have a healthy or unhealthy new normal: ***A healthy new normal*** requires you to focus on the things you can control – such as your diet, exercise, compliance with doctor’s orders, self-advocacy with medical teams, self-

education about PH – so you feel empowered. *An unhealthy new normal* fixates on things outside your control and encourages feelings of helplessness, sadness, frustration and anger.

- Be gentle & patient with yourself, finding a new normal may take time and everyone's journey is unique
- You are not alone when experiencing the frustration of the new normal; reach out to others through support groups
- Remember it's ok to have bad moments – but not ok to fixate on those feelings

## **SESSION 5: Managing side Effects of PH Medications**

### **Session description:**

Dealing with PH symptoms can be emotionally and physically demanding. PH therapies are used to help alleviate the symptoms of the disease but can also cause side effects that one must learn to manage.

### **Learning objectives:**

- Understanding the common side effects that PH therapies can produce
- Decide how you and your PH care team can communicate to discuss side effects that become demanding to optimize your therapy and treatment plan

### **Strategies to manage common PAH medication side effects**

#### ***When you start a new medication:***

- Ask your pharmacist about the top likely side effects that you may encounter with your PAH medications
- Ask about medication prescriptions (over the counter & prescription) that may help alleviate the side effects of your PAH medications

#### ***After you have started:***

- Communicate with your pharmacist / medical team about the adverse effects you experience
- There are many solutions that will allow you to continue taking the medication – do not stop the medication without the approval and intervention of your medical team
- Ask for help from your pharmacy and if there is a product-specific support programme or online phone resource – make contact

## **SESSION 6 - The journey to a PH Diagnosis**

I attended the following session which was presented by doctors. I found it most informative. However, while I have taken notes on the session, I will not report on it since I have neither a medical nor nursing background.

**Session Description:** The panellists discussed the overwhelming number of tests required for a correct PH Diagnosis. They provided an overview of the diagnostic process, discussed the goals of the various tests and explained what information the test results provided to clinicians.

## **SESSION 7 – The basics of PH and WHO Classification Groups**

This session was also presented by doctors and I would be apprehensive about reporting on the talk which I found very interesting

### **Session Description**

Panelists reviewed the basics of PH: how the heart is affected by high blood pressure in the lungs, the difference between high blood pressure in the lungs and high blood pressure throughout the rest of the body, as well as common PH symptoms. Panelists also discussed the different types of PH and the reasons behind the extensive testing that is required for accurate diagnosis and choosing the best treatment plan.

### **Informal Meetings:**

I met with Kristin Books, Director of Fundraising Events in PHA. I intend keeping in touch with Kristin and hopefully we may benefit from ideas and innovative ideas from the US. I also met with Azalea Candelaria, Vice President, Development. We discussed the problems encountered with constant fundraising and the need for motivation without placing pressure on anybody.

We also discussed the importance of Advocacy. How we should encourage our patients to become advocates for PH by making themselves known to their elected officials. The PHA in the US have a very strong Advocacy and Treatment access team who are constantly fighting on Capitol Hill for the needs of patients. Their current advocacy priorities are:

- To reduce out-of-pocket costs and other barriers to quality care for individuals with PH
- Fight for PH care – which is driven by the recommendations of an expert physician and not insurance company preference
- Advocate for health care policy that meets the needs of the PH community
- Advance research on PH causes, treatments and potential cures

## **Closing Ceremony**

### **Keynote speaker: Rebekah Calverley, young adult with PH**

Rebekah shared her journey from being diagnosed with PH as a toddler and how she found ways to cope with the limitations she was presented with. She spoke of how determined she was to live a full and rewarding life. She became an opera singer, an equestrian, an international corporate banker and a PHA fundraiser.

Rebekah told the story of how she was born in Auckland, New Zealand. She was unwell a lot as a baby and when she was three years old she was diagnosed with a large hole in her heart and her parents were told it was unlikely she would make it to 5 years of age.

When she was eight, her family moved from New Zealand to New Jersey with her Dad's job transfer. She became a patient of Dr Diane Kerstein at the Paediatric PH Centre at Columbia University Medical Centre, which was one of the nation's first PHA accredited centres of Comprehensive Care.

Prior to moving to the US, Rebekah was a keen equestrian, loved singing and spending her days on the ocean. When she was a young girl she was conscious of her limitations but continued trying to keep up with her class mates in the various school athletic activities. She used to run sprints during PE or try to walk and talk at the same time – however she would always end up in the school nurse's office on oxygen etc. She eventually accepted her limitations. Within the constraints of her illness, she continued horseback riding for several years and began taking voice lessons, performing opera recitals and singing in her church choir.

In college, she majored in Finance and Accounting. She was Student President of the Business school and worked several part-time jobs. She has recently moved into a middle management position with an Australian bank in New York.

Rebekah spoke very emotionally about the support given to her by her family. Her parents Jacinta & Richard have always been there for her and supported her in everything she wanted

to do. Because of her determination and stubbornness – her Mum often said ‘God made your head stronger than your heart’. She described her sisters as her ‘Bodyguards, her Entourage, her Supporters, her Advocates and her Protectors’. Nothing was impossible when they were growing up – if Rebekah was unable to keep up with others, her sisters just gave her a ‘piggy back’ – To this day they are there for her, looking out for her at all times.

She ended her wonderful & emotional presentation with an amazing recital of Puccini’s ‘*O Mio Babbino Caro*’

**Regina Prenderville**  
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