## PHA Connects: PH Community Workshop – Boston Agenda

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Duration (Min.)</th>
<th>Session Format</th>
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<tbody>
<tr>
<td>8:00 – 9:30am</td>
<td>Registration &amp; Continental breakfast</td>
<td>60</td>
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<tr>
<td>9:00 AM – 3:30 PM</td>
<td>Kid’s Room</td>
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<td>Childcare staffed by professionals.</td>
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<tr>
<td>9 – 9:50</td>
<td>General Session #1</td>
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<td></td>
<td>Welcome and Introduction to PH</td>
<td>10</td>
<td>Matt J. Granato, LL.M., MBA PHA</td>
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<td>Co-Chair Welcome</td>
<td>5</td>
<td>Mary P. Mullen, MD, PhD Eileen Harder, MD</td>
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<td><strong>PH 101: Understanding Your PH Diagnosis</strong></td>
<td>30</td>
<td>Eileen Harder, MD Brigham &amp; Women’s Hospital</td>
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<td>Testing for a pulmonary hypertension (PH) diagnosis can be overwhelming.</td>
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<td>There are different tests, including echocardiograms, right heart catheterizations, pulmonary function tests and sleep studies that can help differentiate between the five PH groups. Understanding how the results of these tests lead to different PH diagnoses is essential to comprehending the best treatment options. This presentation will provide an overview of the diagnostic process and what information test results provide to clinicians.</td>
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<tr>
<td>9:50 – 10</td>
<td>Break &amp; Exhibits</td>
<td>10</td>
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<tr>
<td>10 – 10:50</td>
<td>Breakout sessions #1 (3 concurrent)</td>
<td>50</td>
<td>Mary P. Mullen, MD, PhD</td>
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<td></td>
<td><strong>Understanding Childhood Onset PH</strong></td>
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<td>Timothy Klouda, DO</td>
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<td>Learn about the symptoms, diagnostics, causes and types of pediatric PH from our panel of pediatric specialists. It is important to understand the treatment options and how to manage the disease from childhood to young adult. This session provides an opportunity to get answers to key questions and to gain valuable information to help manage childhood onset PH over the long-term.</td>
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<td>Katie Fabbrucci, MSN, RN, CPNP</td>
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<td>Boston Children’s Hospital</td>
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<td>Boston Children’s Hospital</td>
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**Assessing Risk in PAH: Is Your Treatment Plan Working?**
You may hear the term risk stratification from your healthcare provider, but what does that mean? It is an important step in your overall care to help determine if your treatment plan is working. It is important you get regular evaluations to help guide your treatment plan. Learn about using risk stratification as a tool in your treatment plan, what to expect during an assessment, and why it is important for your overall health.

**Coordinated Care for PH Patients**
This informative session will focus on the essential aspects of coordinated care for patients with Pulmonary Hypertension (PH). Coordinated care plays a crucial role in ensuring comprehensive and holistic management for PH patients. We will explore specific topics such as incorporating medical therapy into the school/work environment, coping with surgery, the significance of multidisciplinary team (MDT) care, and strategies for building a strong care team. Participants will gain valuable insights into enhancing patient outcomes and improving overall care coordination for individuals living with PH. Together, we will explore ways to enhance care coordination, improve patient experiences, and promote better outcomes in the management of PH.

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<tr>
<th>Time</th>
<th>Event</th>
<th>Speakers</th>
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<tr>
<td>10:50 – 11:20</td>
<td>Break &amp; Exhibits</td>
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| 11:20 – 12:10pm | Breakout sessions #2 (3 concurrent) **Understanding Genetic Risk in PAH** | Carrie L. Welch, PhD  
Columbia University Irving Medical Center  
Mary P. Mullen, MD, PhD  
Boston Children’s Hospital  
Katherine Cox-Flaherty, MD, ScM  
Alpert Medical School at Brown University |
Benefits of Exercise and Diet
A proper diet and physical exercise are key to effectively manage pulmonary hypertension (PH) for patients. Panelists will discuss the impact of lifestyle choices on PH. You will learn how exercise can improve cardiovascular health, enhance lung capacity, and increase overall endurance, while a healthy diet can support medication effectiveness and promote optimal well-being. Our panelists will share practical tips, types of exercises, and dietary choices that will allow you to better manage your PH symptoms, improve your energy levels, and enhance your overall quality of life. Don't miss this empowering session aimed at helping you take control of your health and thrive with pulmonary hypertension.

Life with Childhood Onset PH
If you or your loved one were diagnosed with PH as a child or teen, it’s possible you have a variety of questions about PH depending on when you were diagnosed and age. This session will help you to better understand childhood onset PH at the various stages in a young person’s life. With time, there may also be a shift from pediatric to adult PH care. Learn what you need to know about the essential steps to make a smooth transition from pediatric to adult care, including finding the right health care team, understanding the changes in treatment and support systems, as well as building self-advocacy skills.

Josanna Rodriguez-Lopez, MD
Massachusetts General Hospital

Nadine Al-Naamani, MD, MS
Penn Medicine

Timothy Klouda, DO
Boston Children’s Hospital

Molly Gilmore, MSN, RN, CPNP
Boston Children's Hospital

Jessica S. Apostoloff,
Parent of a Child with PH

12:10 – 1:10pm
Networking lunch with Expert Q&A
Keynote presentation
60
All Presenters
Keynote: Colleen Brunetti,
PH Patient Advocate

1:10 – 1:20
Break & Exhibits
10

1:20 – 2:10
Support Group Sessions (3 concurrent)
PH Patients: Support group for PH patients
PH Caregivers: Support group for people who love someone with PH
PH Parents: Support group for parents of a child with PH
50
Patient: Laura Hooley
Caregiver: Mary E. Whittenhall,
MSN, APRN
Parent: Bill O’Donnell
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| 2:10 – 2:50 | **General session #2**  
**Spotlight on PH Research**  
The treatment options for PH continue to expand as PH research advances. This session will review the research process, how it leads to promising clinical trials that discover new therapies and patient registries that aim to advance the field of PH. Attendees will gain insights into ongoing regional clinical trials and learn how patients can participate to support the advancement of these research studies. | 40       | Paul B. Yu, MD, PhD  
Massachusetts General Hospital  
Mary P. Mullen, MD, PhD  
Boston Children’s Hospital |
| 2:50 – 3:00 | **PHA Resources**  
Program Close  
(10 min) | 10       | Matt J. Granato, LL.M., MBA,  
Pulmonary Hypertension Association |