



1

Building Pulmonary Hypertension Centers in Underserved Communities

Rural and Urban Experiences

Hayan Al Maluli, MD

Allina Health Minneapolis Heart Institute

11/14/2022



2

Conflicts of Interest

- None in the last two years



GRAND
ROUNDS



3

Objectives

- Define the state of pulmonary hypertension care in the US
- List challenges to delivering quality PH care
- Deduce and debate solutions for the future of PH




GRAND
ROUNDS




4

How It All Began

- Interest
- Opportunity
- Need




GRAND
ROUNDS




5

How It All Began

- Interest: Confusion about the subject matter led to deep interest




GRAND
ROUNDS




6

How It All Began

- Opportunity: to pursue tailored training at a large center




GRAND
ROUNDS




7

How It All Began

- Need: pulmonary hypertension is a really bad news



GRAND
ROUNDS



8

The Why: PAH Prognosis

- 10-15% mortality per year, 50% at five years
- Untreated, median survival is 2.8 years
- Diagnosis can be delayed and frequently occurs when disease is relatively advanced
 - Historically, the NIH PAH registry showed a mean time to diagnosis of 2.03 years ¹
 - REVEAL: mean time from symptom onset to diagnostic RHC was 2.8 years ²

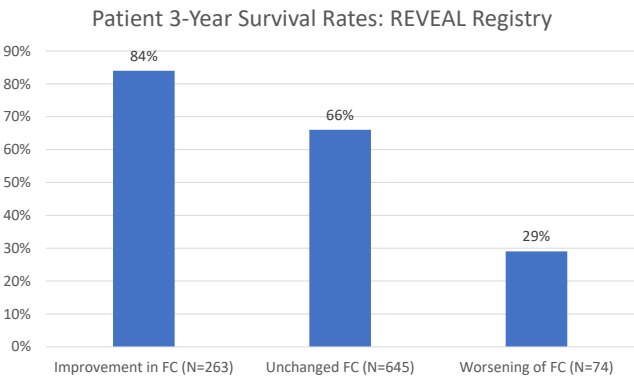
1. D'Alonzo GE, et al. *Ann Intern Med.* 1991;115:343-349.
2. Badesch DB, et al. *Chest.* 2010;137:376-387.



GRAND
ROUNDS



9



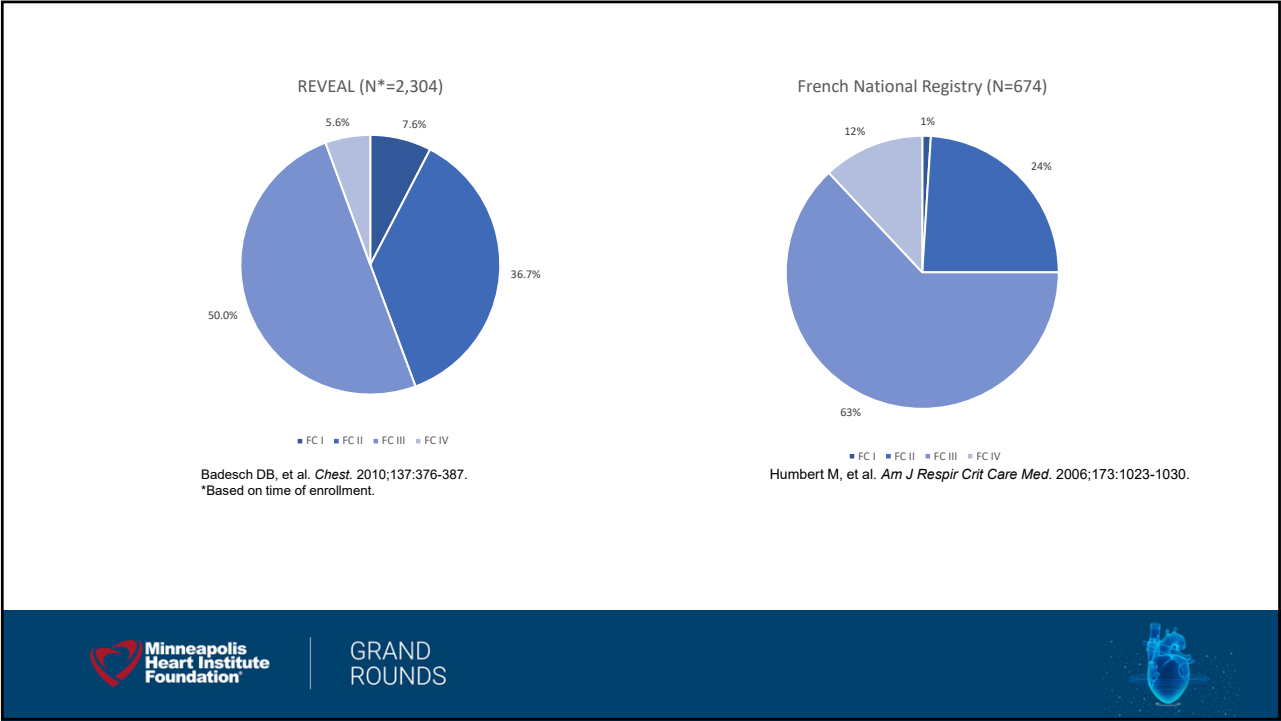
Barst, et al. *Chest.* 2013;144(1):160-8.



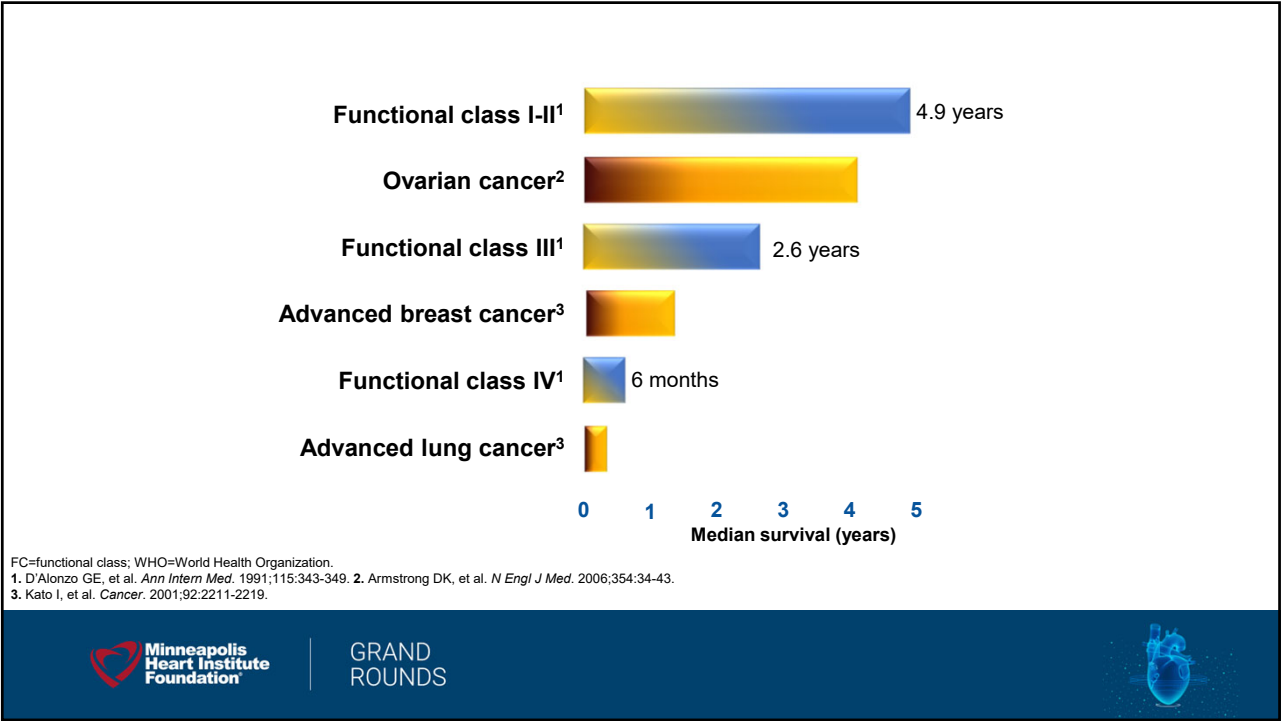
GRAND
ROUNDS



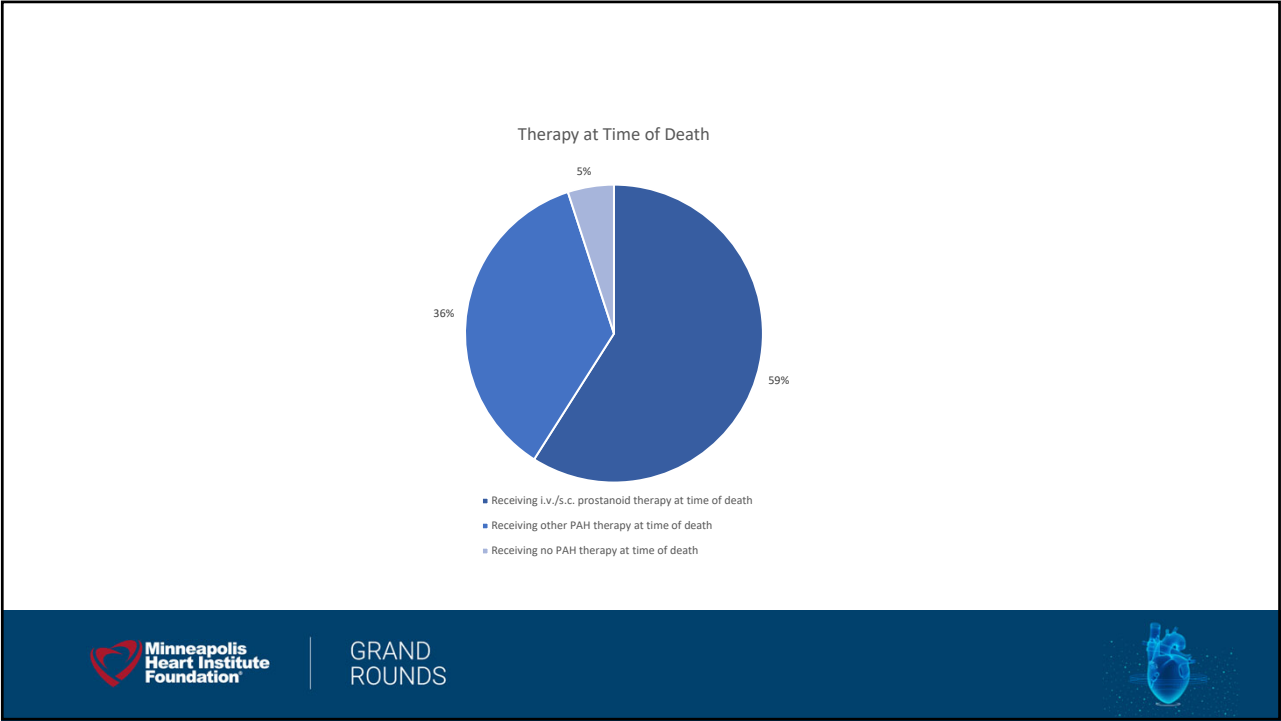
10



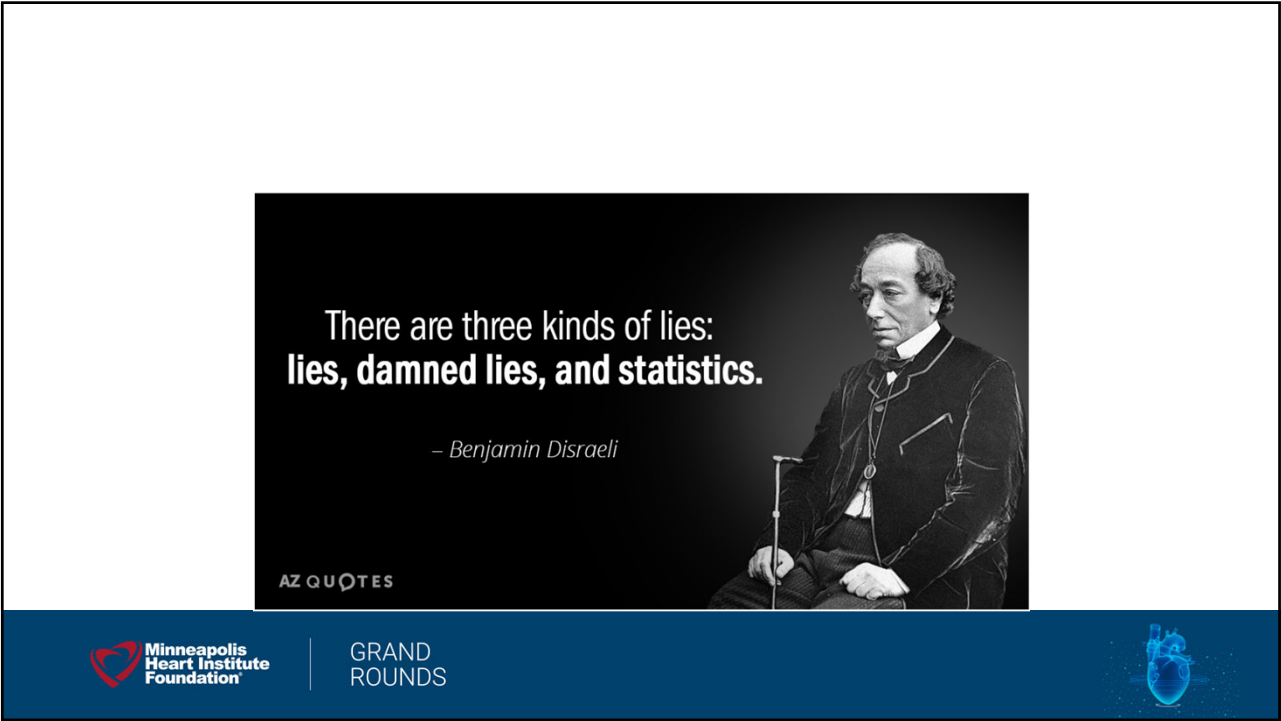
11



12



13



14

MHI Data from Rural MN

- Cath confirmed PAH prevalence is up to 13 times higher than the estimated 15-50 cases/ million compared to national data ¹
- Suggests significant under-diagnosis and consequently worse prognosis
- Experience in ND and St. Paul/ western WI was the same

1. Fenstad et al PH in Rural MN: Prevalence and clinical classification DOI: 10. 1016/j.jhealun.2019.01.1241



GRAND
ROUNDS



15

The State of PH Care in the US

- Most care is centered in large academic centers
- Few scattered providers, different backgrounds with little support
- PH care is either non-existent, exists but is minimal and secondary, or exists and is supported and encouraged



GRAND
ROUNDS



16



17

Layers of Challenges

- Layer unique to the disease process (progressive, deadly, poorly understood and sub optimally investigated)

Layers of Challenges

- Layer unique to the patient (psychological impact, difficult access to quality care, financial burden, administrative burden, family, etc.)



GRAND
ROUNDS



19

Layers of Challenges

- Layer unique to the medications (side effects, access to administration, etc.)



GRAND
ROUNDS



20

Layers of Challenges

- Layer unique to economics of the disease (most drugs are outrageously expensive even when insured, coverage, alternatives, etc.)



GRAND
ROUNDS



21

Layers of Challenges

- Layer unique to the center or facility (extent of commitment (day/night/ weekend, providers, staff training, turn over, facilities, etc.)



GRAND
ROUNDS



22

“A sign of intelligence is that you are constantly wondering. Idiots are always dead sure about every damn thing they are doing in their life”

Sadhguru



Solution

- Recognize the problem
- Build a team and support it



Building a Team

- Patient
- Family
- Insurance
- Specialty pharmacy
- Industry
- Nurses
- Coordinators (RN, APP, administrator)
- Pharmacists
- Institutional leadership
- Providers (NP's, PA's, MD's)



GRAND
ROUNDS



25

Patient Factors

- Social factors
- Psychological factors
- Economics
- Cognition
- Co-morbidities



GRAND
ROUNDS



26

Family

- Technical support especially with infused or inhaled medications
- Transportation
- Housing



GRAND
ROUNDS



27

Insurance

- Insured vs. uninsured
- Type of insurance
- Co-payment (regardless of economic status)



GRAND
ROUNDS



28

Specialty Pharmacies

- Most PH medications are administered via specialty pharmacies
- Often the insurance carrier decides which one to use
- Not all are created equal
- Establishing good relationship is key



GRAND
ROUNDS



29

Industry

- Can be a resource to educate
- Can be a resource to help spread the word
- Excellent connection building network
- Research access
- Conflict of interest issues



GRAND
ROUNDS



30

Nurses

- Day to day care coordinators and bridge between patients, providers, and pharmacy.
- Important to get them involved, empowered, educated, and supported.
- They need to be encouraged to be active in research, conferences, patient support groups, community outreach.



GRAND
ROUNDS



31

Coordinators

- Could be a separate administrative position or a clinical staff member.
- Does the initial and follow up paperwork, after adequate training
- Important to have contingency
- Important to keep them motivated and engaged



GRAND
ROUNDS



32

Pharmacist

- Clinic pharmacist, specialty pharmacy pharmacist, pharmaceutical company pharmacist
- Clinical pharmacist are a great resource



GRAND
ROUNDS



33

Leadership

- Supportive leadership can make or break the program
- Engaged leadership facilitates coordination between service lines, billing department, prior auth, ICU, nursing, pharmacy, etc.
- Advertising the program and promoting its message



GRAND
ROUNDS



34

Leadership

- Politics



GRAND
ROUNDS



35

Providers- APP's

- NP or PA that is trained in PH by an MD or DO. Must be competent in all care aspects of PH
- A resource for RN's and clinical and non-clinical staff and point of contact for patients and referrals.
- The best programs are those that invest as much in their APP's as they do in their doctors



GRAND
ROUNDS



36

Providers - Doctors

- Well trained cardiologist or pulmonologist- No accredited training yet
- Chest or cardiopulmonary medicine specialist: unique abilities not included under one specialty
- Essential: multiple providers who share interest and compliment each other's expertise



GRAND
ROUNDS



37

Providers - Doctors: Training

- Cards: extra time in the ICU, inpt and outpt PH service, hemodyn lab, exercise phys lab, pulm lab, ILD, rheum, lung and liver txt clinics.
- Pulm important to spend time in echo lab and cath labs
- CTEPH clinic, pre/post op evaluation, balloon angioplasty, lung transplant and atrial septostomy
- Conduct PH specific research



GRAND
ROUNDS



38

Providers - Doctors: Practicing PH Specialist

- Involvement in education of staff, colleagues, trainees, community providers, patient support groups, inpatient nursing, etc.
- Attending PH specific conferences, connecting with the PH community
- Conduct and supervise research both self triggered as well as clinical trials participation
- Time dedication



GRAND
ROUNDS



39

The Importance of Competent Providers

- The guidelines recommend to centralize the care of PH patients at “expert centers”.
- Centralization **must** be accompanied by a **robust outreach strategy** to capture patients
- Comprehensive vs. Regional care centers



GRAND
ROUNDS



40

PHA Care Center Designations



- Comprehensive vs. Regional care centers
- Center director
- Coordinator
- Staff and support services (number of patients, including on parenteral, consultant availability, etc.)
- Facility
- Research



GRAND
ROUNDS



41

	 PHA Center of Comprehensive Care	 PHA Regional Clinical Program
Center Director	Must have completed Fellowship in pulmonary medicine, critical care medicine, and/or cardiology	Must have completed Fellowship in pulmonary medicine, critical care medicine, and/or cardiology
	Should be board certified in pulmonary medicine, critical care medicine, and/or cardiology	Should be board certified in pulmonary medicine, critical care medicine, and/or cardiology
	Must have a minimum of two (2) years experience treating PAH after fellowship	Must have a minimum of two (2) years experience treating PAH after fellowship
	<div>Must be an active participant (Organizing/Steering Committee, Presenting/Speaking, Poster Presenter, etc.) in at least one of the following in the last three (3) years:</div> <ul style="list-style-type: none">• Regional Meetings;• National Meetings;• International Meetings; or• PH Task Force	<div>Must be an active participant (Organizing/Steering Committee, Presenting/Speaking, Poster Presenter, etc.) and attended at least 1 in the prior year</div> <ul style="list-style-type: none">• Regional Meetings




GRAND
ROUNDS




42

<div>Must be involved in PH-related education exemplified by <i>some</i> of the following endeavors:</div> <ul style="list-style-type: none">• Educating Center and Hospital Staff• Mentoring Trainees• Involved in Community Outreach• PH-related Committee Work	Must provide ongoing education/mentoring of staff
Should be a member of Pulmonary Hypertension Clinicians and Researchers (PHCR)	Should be a member of Pulmonary Hypertension Clinicians and Researchers (PHCR)
Should have completed thirty (30) hours of CME related to PH over the past 3 years (attending and/or presenting)	Should have completed twenty (20) hours of CME related to PH over the past 3 years (attending and/or presenting)
See "Facilities" section below	When appropriate, Director collaborates and co-manages patients with a regional CCC <ul style="list-style-type: none">• Advanced medical therapies• Advanced surgical interventions• Investigational protocols




GRAND
ROUNDS




43

Center Coordinator	Must be an allied health professional employed by the CCC, practice or institution	Must be an allied health professional employed by the RCP, practice, or institution
	<div><ul style="list-style-type: none">• ≥ 1.0 FTE (can be satisfied by more than one person)</div>	<div><ul style="list-style-type: none">• ≥ 0.25 FTE</div>
	Must be a RN, APRN, PA, RRT or Pharmacist	Must be a RN, APRN, PA, RRT or Pharmacist
	Must be proficient in disease state and with all PAH therapies (oral, inhaled, IV/SQ) and delivery devices	Must be proficient in disease state and with all oral PAH therapies
	Must also be knowledgeable about the approval, initiation and maintenance of all PAH therapies	Must also be knowledgeable about the approval, initiation and maintenance of oral PAH therapies
Must be an active participant in regional / national / international PH congresses (one or more of the following occurred within the preceding three [3] years):	Must be an active participant (Task Force Membership, Organizing/Steering Committee, Presenting/Speaking, etc.) in regional PH congresses	
	<div><ul style="list-style-type: none">• Task Force Membership• Organizing/Steering Committee• Presenting/Speaking (oral, poster, meet-the-expert, CME, etc.)</div>	




GRAND
ROUNDS




44

Program Staff and Support Services	Physicians' effort towards PH program, including clinical care, clinical research, and administrative duties, should total at least 0.75 FTE	Not applicable
	<ul style="list-style-type: none">Director's efforts towards PH program should be at least 0.5 FTE	
	Should actively be managing a substantial cohort of patients	Should actively be managing a minimum of 25 patients
	<ul style="list-style-type: none">≥ 75 patients with either Group I or Group IV PH diagnosis (Simonneau G, et al. J Am Coll Cardiol. 2013; 62(25S): 34-41; http://www.ncbi.nlm.nih.gov/pubmed/24355639)Mitigating factors will be taken into consideration (e.g., regional population, Center catchment area, proximity to other Centers, duration of Center's existence, tenure of Center director etc.)	
	Must follow available diagnosis and treatment consensus guidelines when possible ¹	Must follow available diagnosis and treatment consensus guidelines when possible ¹




GRAND
ROUNDS




45

Research	<i>*CCC demonstrates a strong commitment to clinical research, as a part of the larger PH community's efforts to improve outcomes and find a cure.*</i>	
	Center staff (physicians and/or coordinators) must have actively participated in at least three (3) separate IRB-approved PH clinical investigations within the previous three (3) years.	Not applicable
	<ul style="list-style-type: none">May include sponsored research or institutional initiated single or multi-center studiesMay include therapeutic or non-therapeutic investigations (e.g. pharmacologic, non-pharmacologic, genetic, epidemiologic, or mechanistic studies)One of the three IRB-approved studies may be a multi-center registryActive participation requires enrollment of subjects into at least one of the aforementioned clinical investigations, other than a registry	



GRAND
ROUNDS



46

Is the Designation Important?

- From a public image standpoint, it absolutely is
- But more important is to understand and implement the criteria in order to provide a true comprehensive care
- Long term commitment in a quality PH program would certainly pay off for the patients and the institution
- Can you afford not to do it?



GRAND
ROUNDS



47

The reasonable man adapts himself to the world...




GRAND
ROUNDS




48

....the unreasonable one persists in trying to adapt the world to himself.



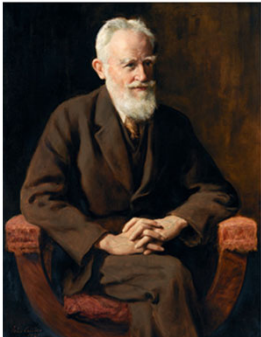
GRAND
ROUNDS




49


....Therefore, all progress depends on the unreasonable man”

- *George Bernard Shaw*







GRAND
ROUNDS



50

Questions?





GRAND
ROUNDS

