

Symptom Management: Supplemental Oxygen and Other Supportive Therapies for Patients with Interstitial Lung Disease



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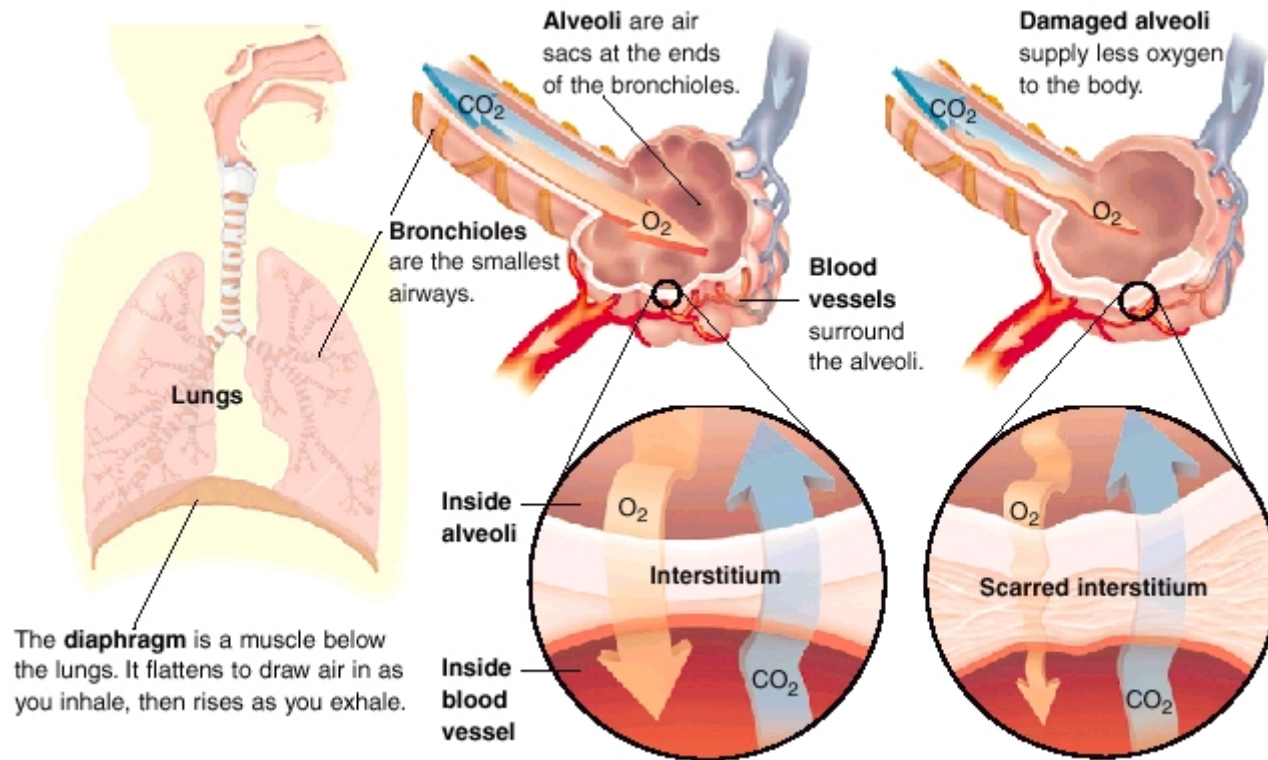
No Financial Disclosures



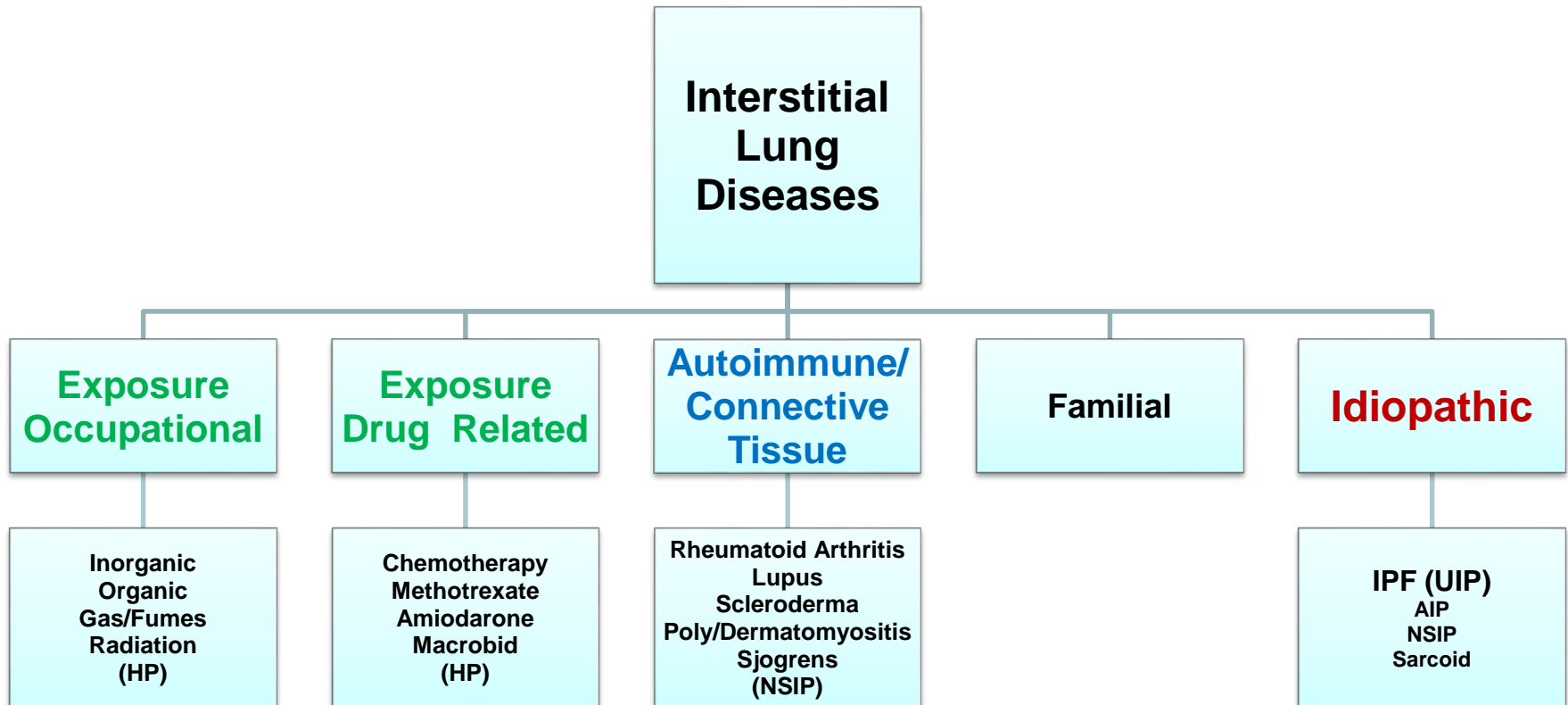
Interventions to Manage Symptoms



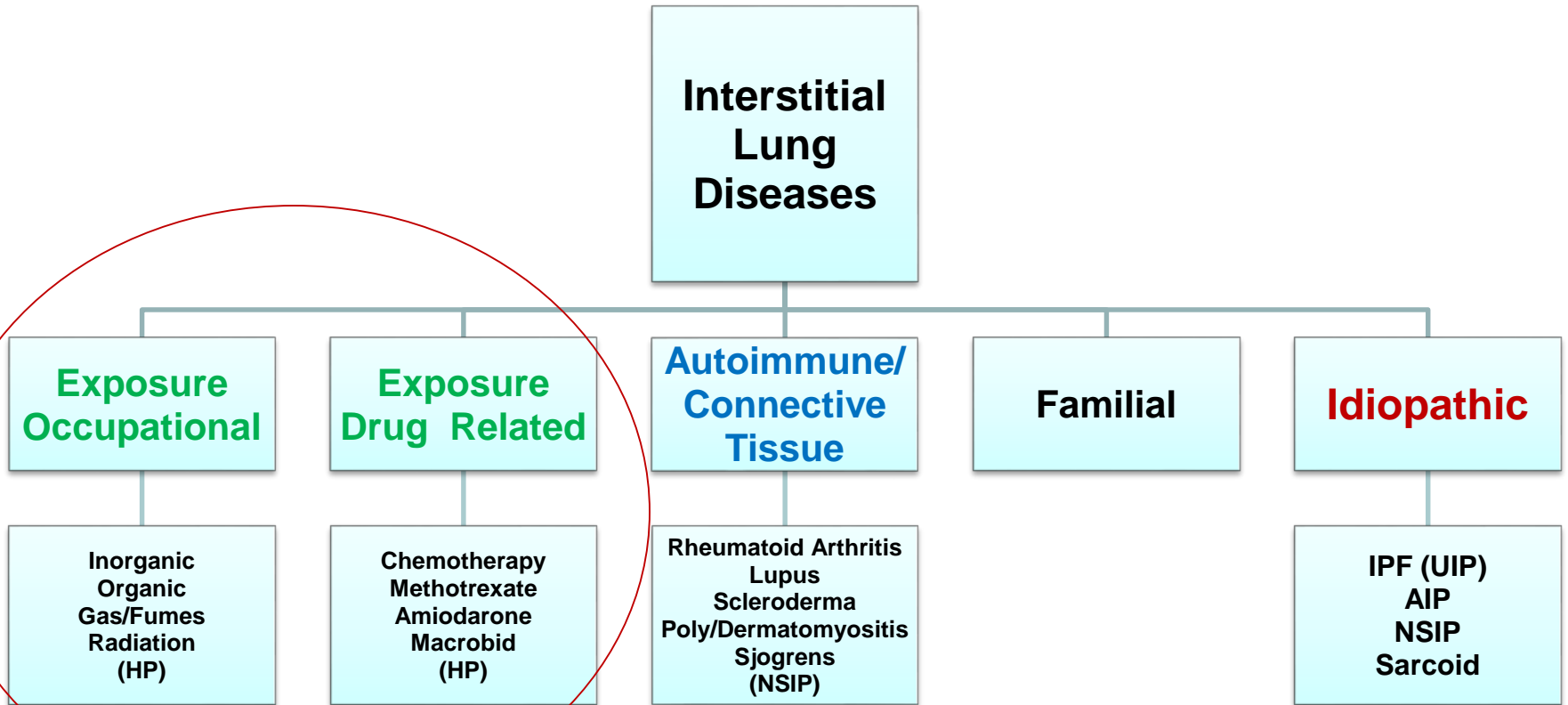
Education: Etiology of ILD



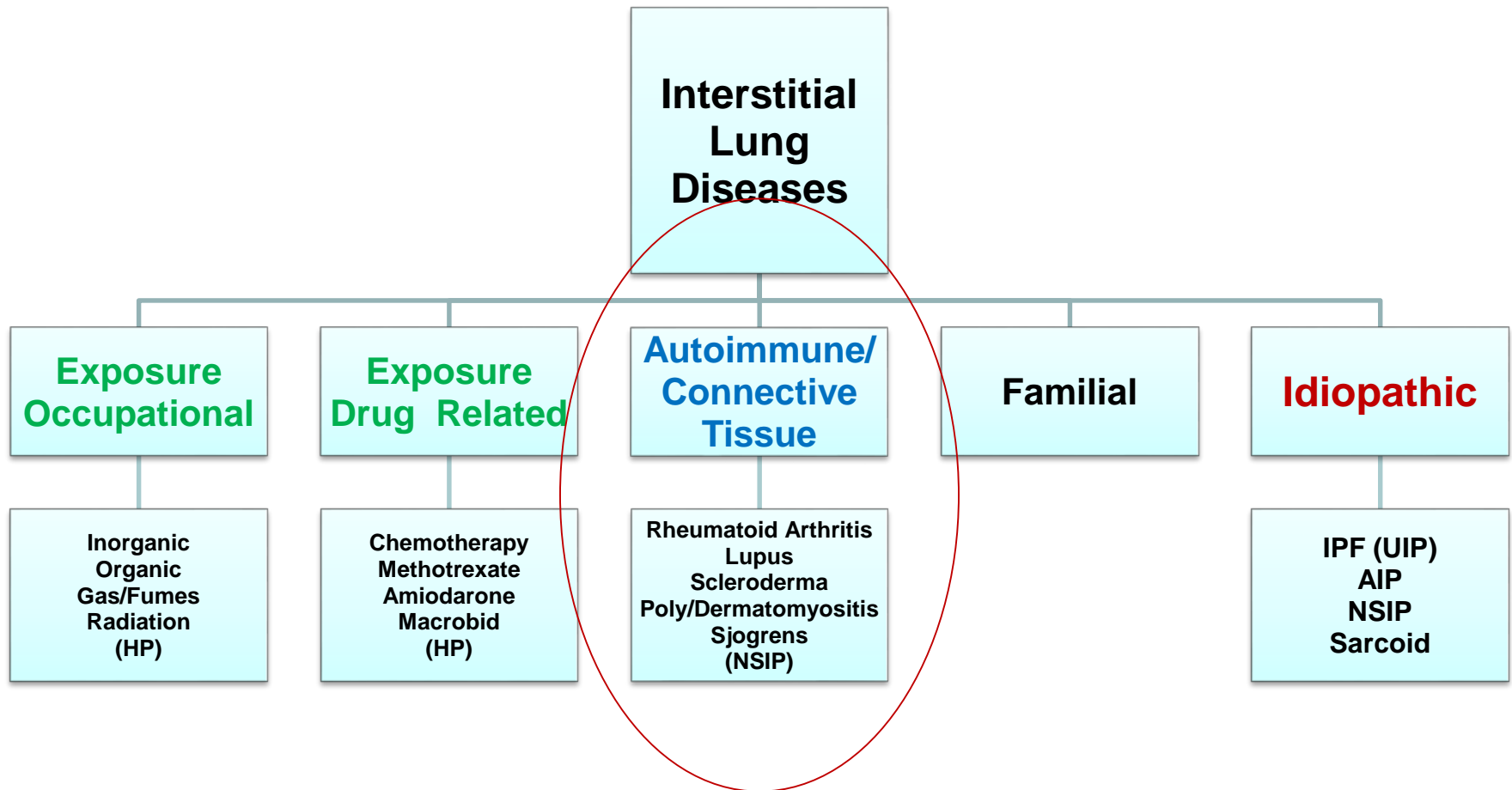
Education: Classification of ILDs



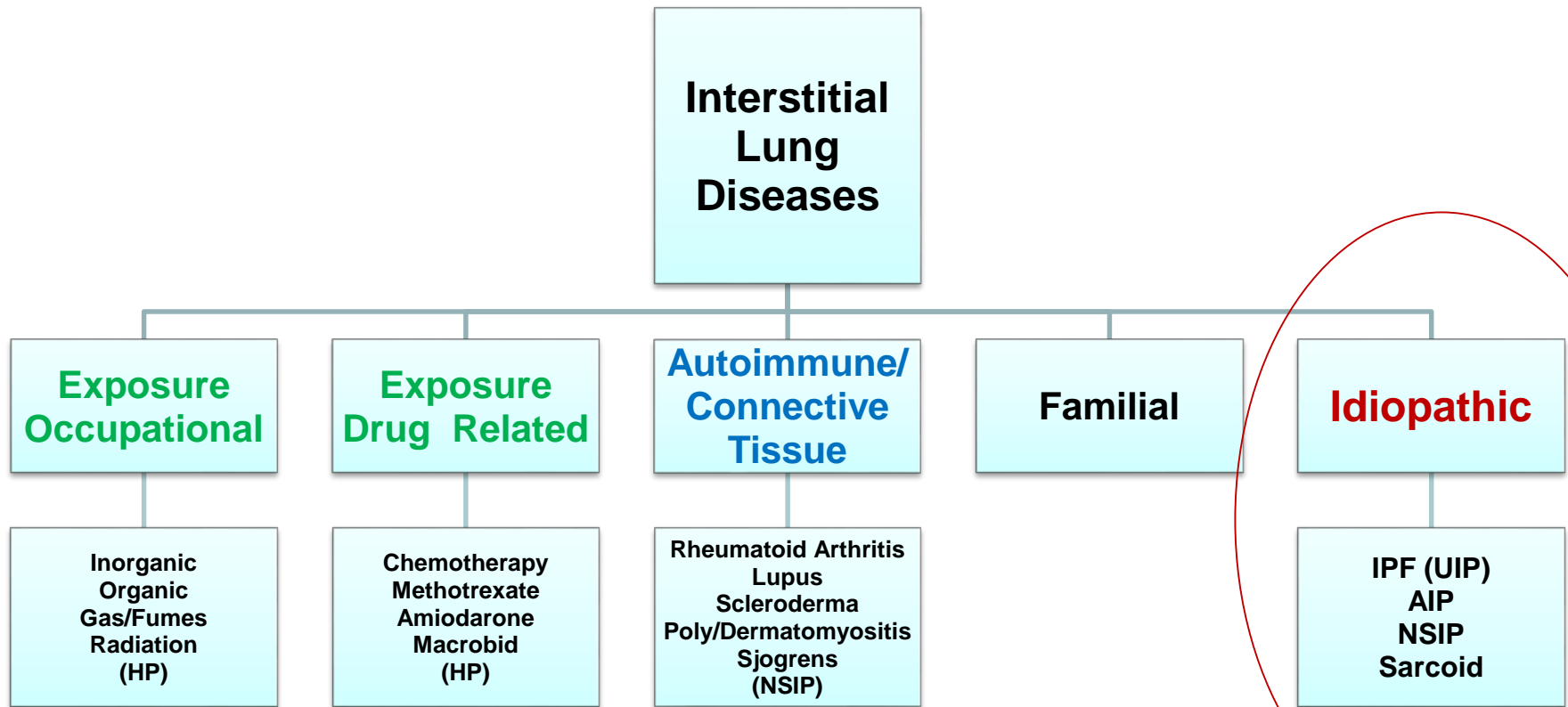
Education: Classification of ILDs



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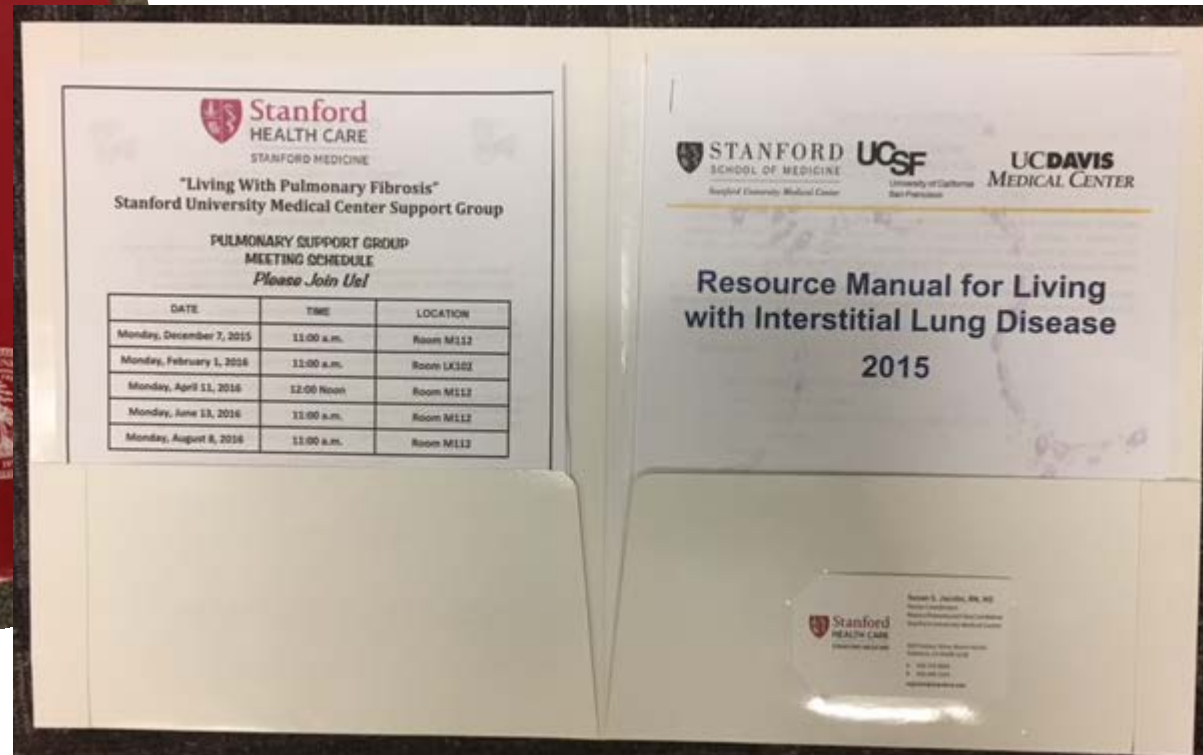
Education: Classification of ILDs



Education

- How and When?
 - “ILD New Patient Packet” at new pt. visit
 - List of program personnel and contact info
 - Pulmonary Fibrosis Foundation (PFF) or other ILD educational handouts
 - List of local Pulmonary Rehabilitation programs
 - Oximeter and oxygen information as needed
 - Support Group contacts or schedule
 - “Cough Tips” handout
 - Tailor to the patient (Scleroderma, Sarcoid...)
 - At minimum, a single page with list of resources

Education



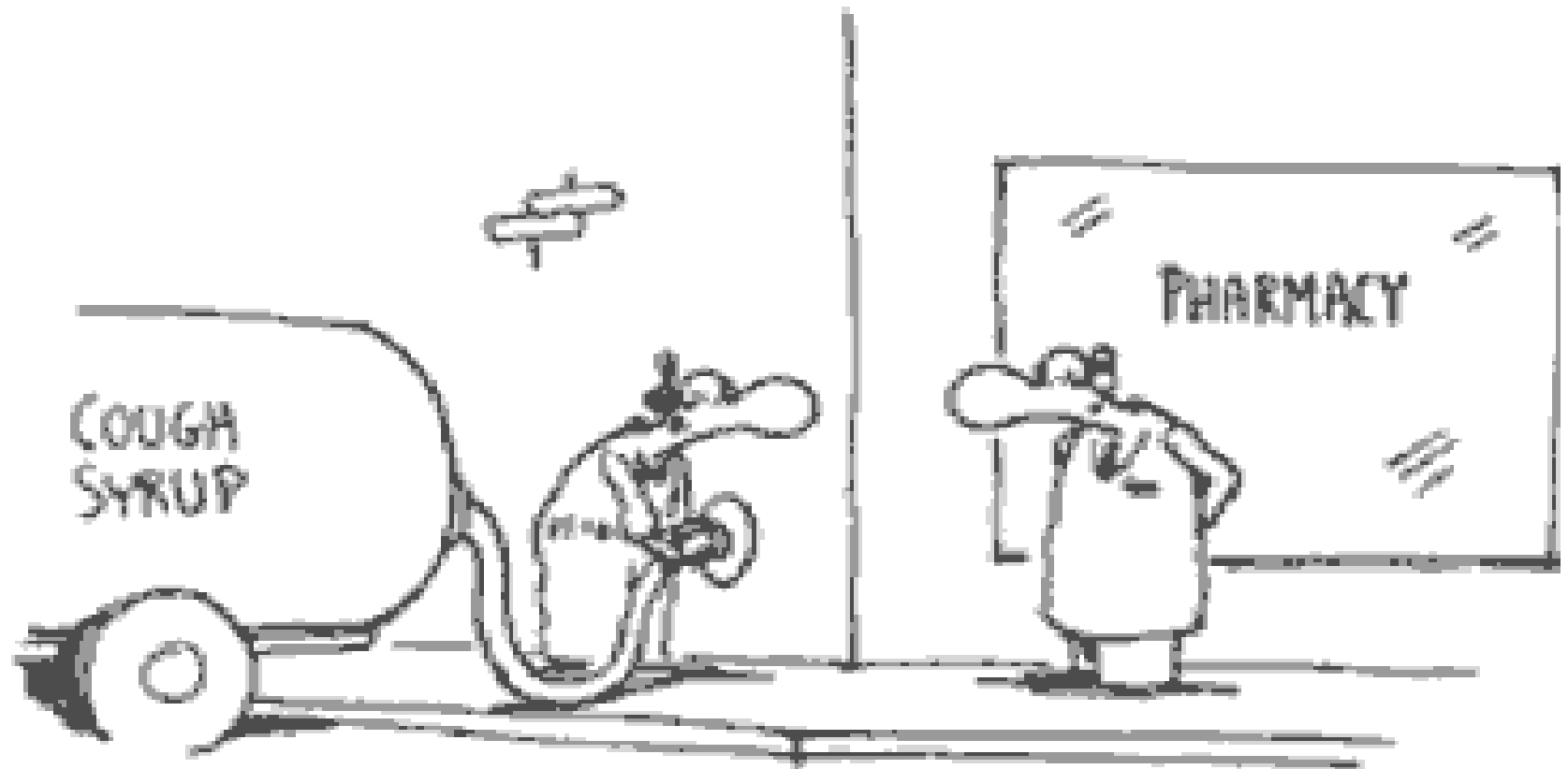
Education



Education: Key Points

- Written resources at first visit
- Tailored to diagnosis
- Individualized to changes in pt's. condition
 - Oxygen
 - Palliative Care
 - Hospice
 - Caregiver Information
- Keep resource file in clinic

Cough



Cough in ILD

1. Chronic cough:
 1. 9-33% in general population,
 2. Up to 80% in IPF
2. Frequency: 24 hr. cough counts
 1. IPF: 226-520
 2. Asthma or COPD: 62
 3. COPD ex-smokers: 118
3. The urge to cough is not relieved by coughing

Cough: Patient's Perspective:

(email from patient J.K., IPF, hospice care)

- **Physical Sensations:**

- “Cannot stop cough or catch my breath which is a terrible sensation;
- With concentrator set at 15MLS of O₂ and finger Oximeter indicating 98% and heart rate of 70-80. O₂ sat goes down into the lower 80's/70's and heart rate goes up to 125, sides, stomach and ribs hurt. I end up soaking wet from sweat and totally exhausted..... It hits me so hard that my energy/stamina takes about 2-3 hours to return.
- Cough used to be mid afternoon to early evening. Then it started when I got into bed. Now it will start anytime of the day but it is now also happening during the night, waking me from what has been a good undisturbed sleeping pattern.”

- **Emotional sensations:**

- “I always feel like this is the one where I'm in the final phase of IPF and my life will slip away”

“If I Could Just Get Rid of the Cough”



- Embarrassment
- Sick to stomach
- Retching
- Incontinence
- Headache
- Ache all over
- Breathlessness
- Hurts to breathe
- Exhausted
- Unable to do activities
- Dizziness
- Rib fractures
- Sleep interruption
- Can't talk/phone, sing, laugh
- Decreased socialization
- Change in lifestyle

Objective Cough Frequency in IPF

- The greater the cough frequency, the worse the patients' rating of their cough-related quality of life
- There was no correlation between pulmonary function tests and cough frequency, except for total lung volume
- Patients' estimation of cough severity correlated well with the cough counter device's results

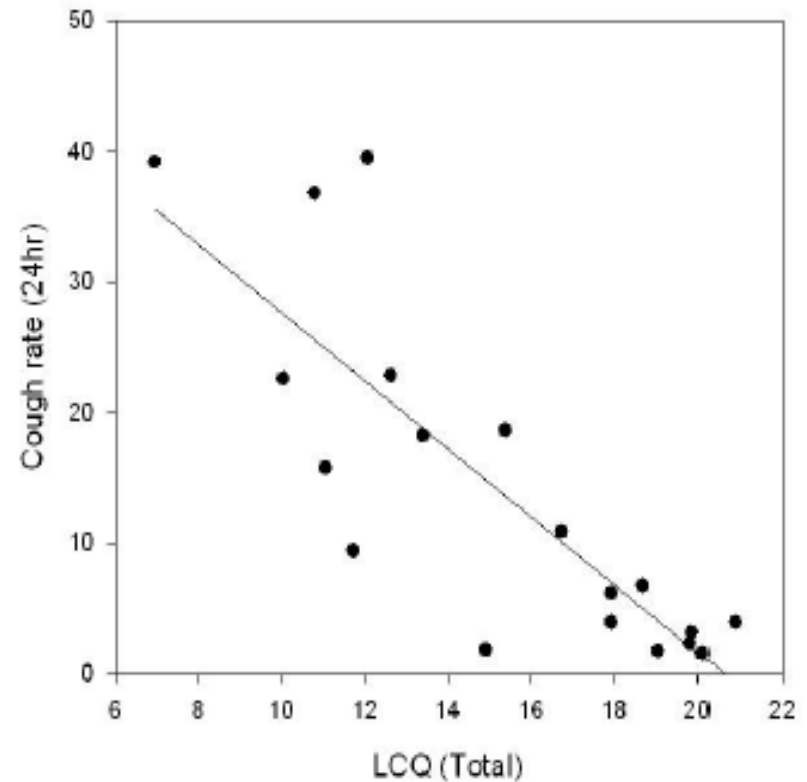


Figure 2 Objective cough frequency (24 hour cough rate) and the total score from the LCQ.

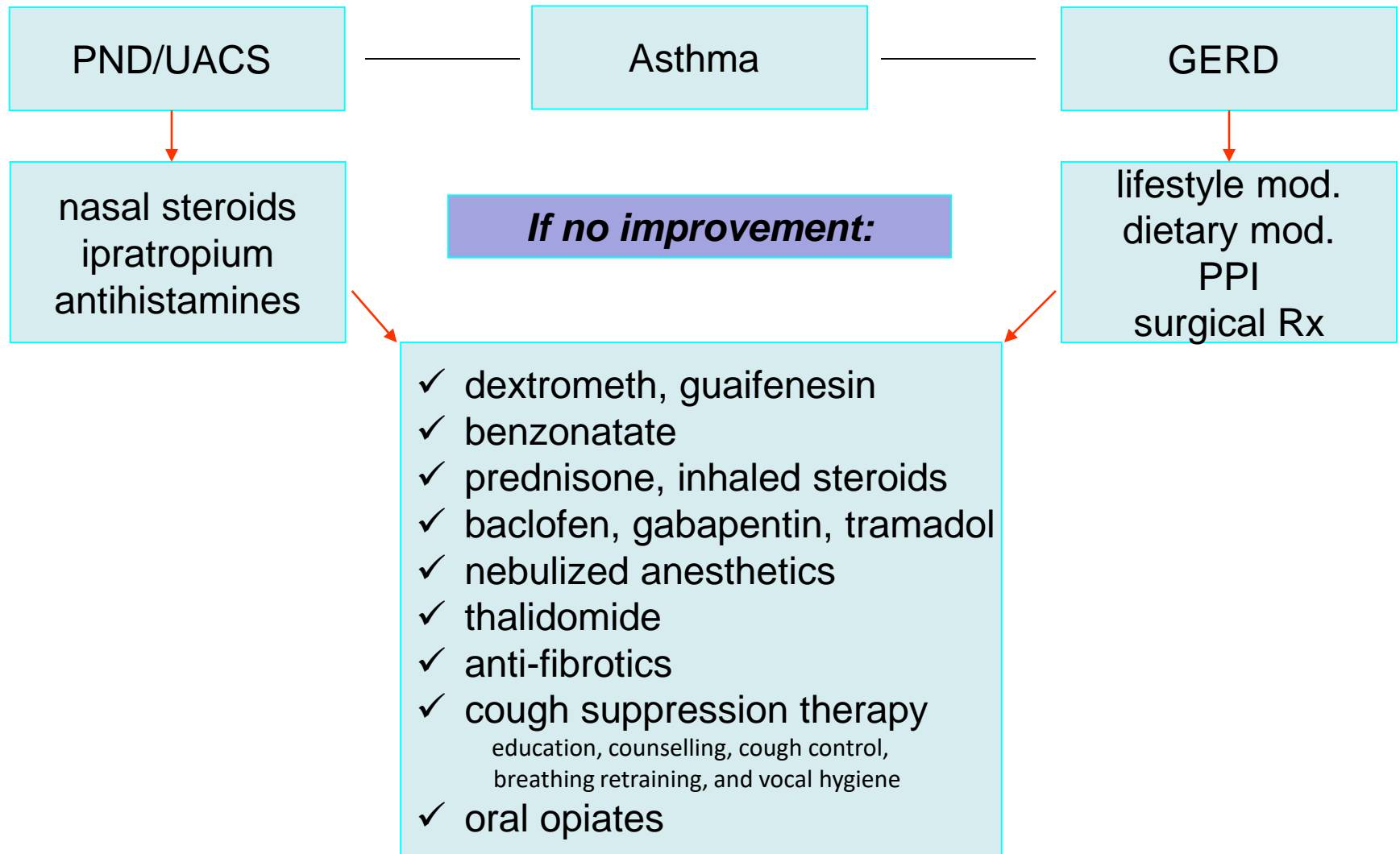
Mechanisms of Cough in IPF

1. No correlation between baseline cough severity (VAS) and FEV1, FVC, TLC, Dlco
2. Concentration of capsaicin needed to induce cough significantly lower in IPF pts. vs healthy controls
3. No correlation between cough sensitivity to capsaicin and PFTs, HRCT severity, and VAS
4. All 6 prednisone-treated pts. decreased cough by VAS and sensitivity to inhaled capsaicin and SP
5. Sputum in IPF pts. had increased neutrophils, lymphocytes, sputum albumin and neurotrophins as compared to normals

Mechanisms of Cough in IPF

1. Inflammation occurs in proximal bronchial epithelium where sensory innervation is greatest
2. Increased neurotrophins in IPF sputum could affect reactivity, differentiation, and proliferation of sensory nerves = cough
3. “These findings suggest functional up-regulation of lung sensory neurons in IPF and the possibility of abnormalities in the proximal bronchial epithelium”
4. Mechanical ‘pull’ on airways may also trigger cough
5. MUC5B polymorphism may be associated with cough severity in IPF patients ()

Treatment of Cough



ILD Patient-Reported Cough Management Strategies: Don't Move, Don't Talk.

S.S. Jacobs, RN, MS, J.J. Swigris DO, MS, G.D. Rosen, MD,
Stanford University Medical Center, Stanford, California, United States.

•Patient-Reported Strategies to Decrease Cough (N=105):

- Lozenges with cough suppressant/oral anesthetic (especially before making phone call, during 'social times')
- Warm liquids - honey and lemon in hot water
- Ginger tea, turmeric
- Sips of water, ice chips, Biotene spray (moisture)
- Chewing/swallowing carefully, slowly (MCTD pts)
- Avoiding irritants, triggers
- ↑ oxygen during coughing as needed
- Hypnosis
- Yoga/relaxation/slowed breathing techniques
- Nothing (29%)



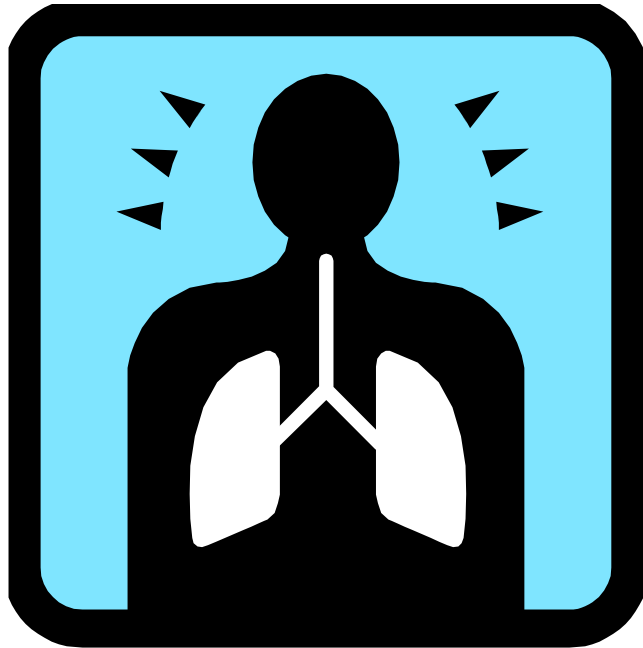


Cough: Key Points



- Research/evidence:
 - IPF patients have ‘up-regulated’ airways (Hope-Gill et al. AJRCCM 2003)
 - Prednisone decreases cough sensitivity and frequency (Hope-Gill et al. AJRCCM 2003)
 - Thalidomide decreases cough scores and increased QOL scores in IPF patients but has associated toxicity (Horton et al. Ann Intern Med 2012))
 - IPF patient estimates of how often they cough are extremely accurate (Key. Cough 2010)
 - Mechanical percussion on the chest wall produced cough in 85% of IPF pts. compared to 17% of healthy control subjects (Jones et al. BioMed Central 2011)
 - Cough impacts QOL for all types of ILD patients (Jacobs et al. AmJRespirCritCare Med 2014, A2455)
 - Many ILD patients may have more than one cause of their cough
 - Cough predicts prognosis in IPF (Ryerson et al. Respirology. 2011)
- Treatment:
 - Cough has not been improved by any of the approved or investigational IPF drugs
 - Most patient-reported strategies include decreasing activity and socialization
 - Management is multi-faceted and includes ruling out other causes of cough, educating the patient on strategies, trying low dose steroids and narcotics, and considering alternative Rx such as cough suppression training or hypnosis

Dyspnea



Mechanisms of Dyspnea

Scarring

Decreased Compliance

Ventilatory Restriction

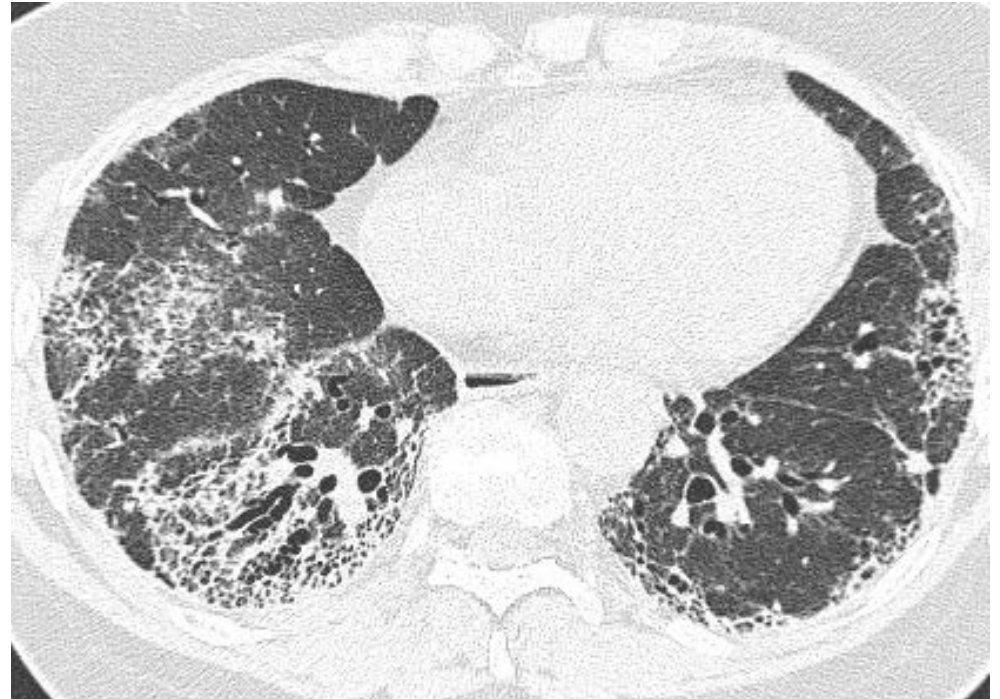
Diffusion Impairment

V/Q Mismatch

Increased WOB

Rapid Shallow Breathing

Dyspnea



← Lung receptors, hypoxemia, deconditioning, anxiety and depression

First Line Treatment for Dyspnea in ILD:

Pulmonary Rehabilitation

Study	Sample	Δ 6MW, m	Dyspnea	QOL
Dowman et al 2017 RCT	142 ILD	25	Improved	Improved
Nakazawa et al 2017 Review	NA	NA	Improved	Improved
Ryerson et al 2014	54 ILD	57	Improved	Improved
Holland et al 2012	44 ILD	21	Improved	NA
Huppman et al 2013	402 ILD inpt.	46	Improved	Improved
Kozu et al 2011	65	31 (MRC 2)	Improved	NA
Swigris et al 2011	21	62	Fatigue improved	SF36 non sig
Garvey 2010 Review	NA	NA	Improved	Improved
Salhi et al 2010	11 RLD	107	Improved	SGRQ non sig
Ferreira et al 2009	99	56	Improved	NA
Holland et al 2008 RCT	57	35	Improved	Improved
Nishiyama et al 2008 RCT	30	42	No Change	Improved
Jastrzebski et al 2006	31	NA	Improved	Improved
Naji et al 2006	26	NA	Improved	Improved

Impact of Exercise on Dyspnea



- Builds endurance
- Strengthens muscles
- Desensitization to SOB
- Improves mood
- Facilitates independence, travel, and socialization
- Maintains ideal weight
- Decreases anxiety, panic
- *Does not change PFTs*
- <http://www.cspr.org/find-a-program>



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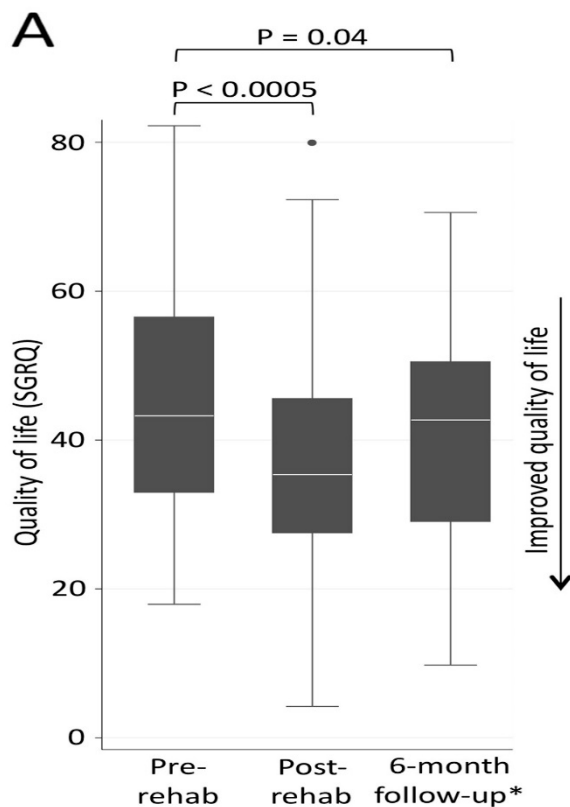


Pulmonary rehabilitation improves long-term outcomes in interstitial lung disease: A prospective cohort study

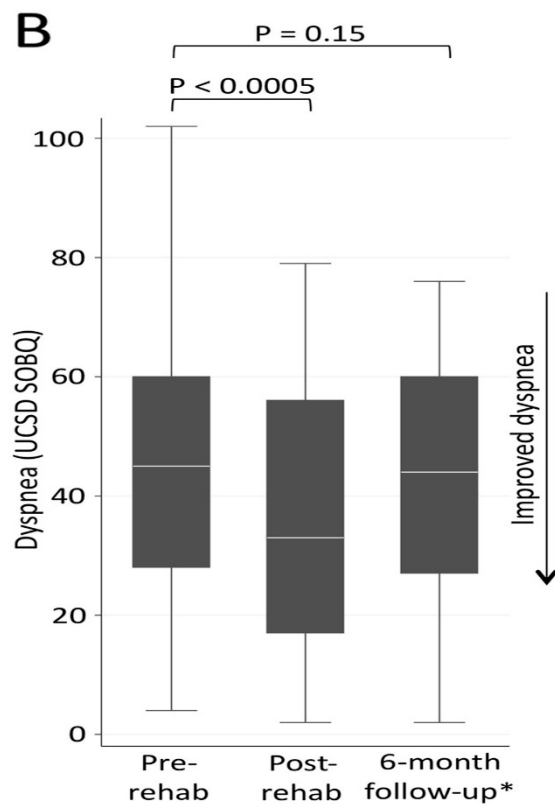
Christopher J. Ryerson , Cindy Cayou , Fiona Topp , Lana Hilling , Pat G. Camp, Pearce G. Wilcox , Nasreen Khalil , Harold R. Collard , Chris Garvey

- **Methods:**
 - 54 ILD patients recruited from 3 PR programs (22 with IPF)
 - 6MWD, QOL, dyspnea, depression, physical activity measured pre, post, and 6 months post program
- **Results:**
 - 6MW improved 57.6 m post ($p < 0.0005$), and 49.8 m 6 mo f/u ($p = 0.005$)
 - Low baseline 6MWD= only predictor of improvement
 - Change in 6MWD predicted change in QOL
 - ILD patients with low baseline 6MWD had greater benefit from PR

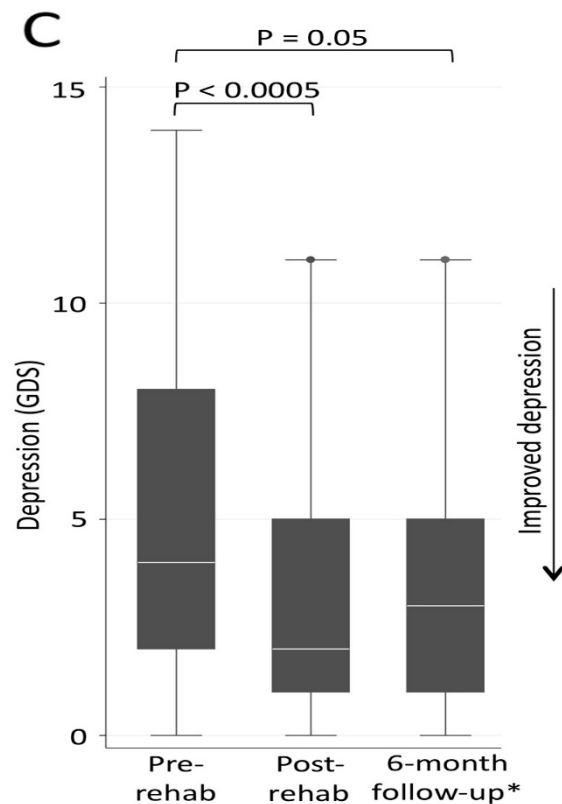
Impact of PR on QOL in ILD Pts.



QOL



DYSPNEA



DEPRESSION



Other Rx for Dyspnea

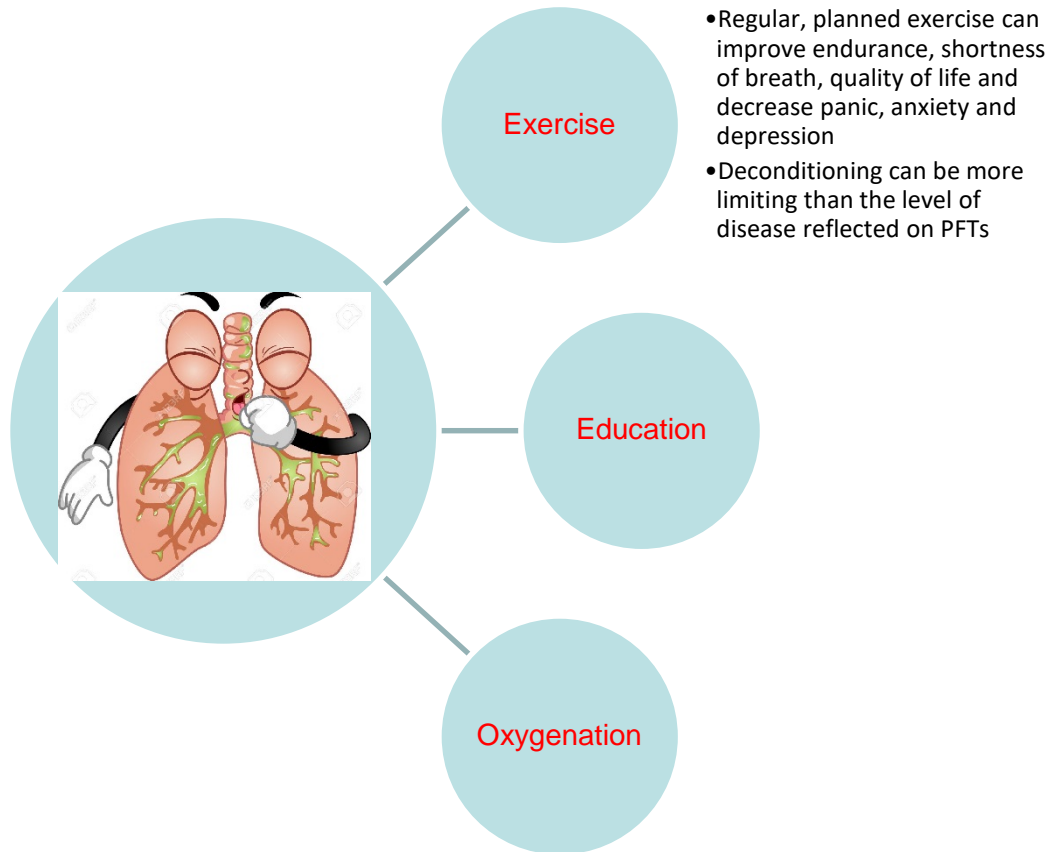


- Pursed lip breathing/breathing retraining
- Fan/cold air/open windows
- Relaxation/visual imagery/meditation
- Distraction: headphones, social interaction
- Yoga (modified)
- Small meals
- Ideal body weight
- Oxygen if hypoxemic
- Opiates/Narcotics/Anti-anxiety drugs



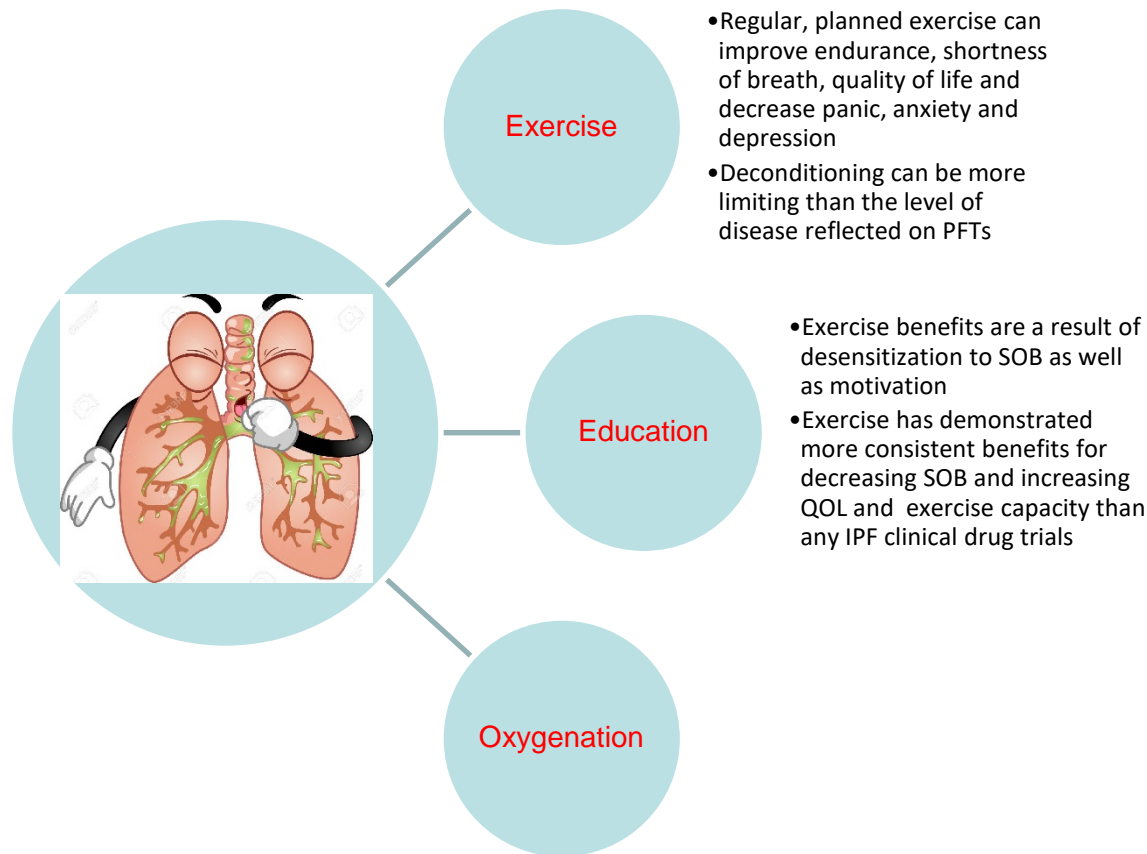
Dyspnea: Key Points

- “Complex interplay between mechanical, neurologic and psychological factors” (Garibaldi and Danoff, Respirology 2016)



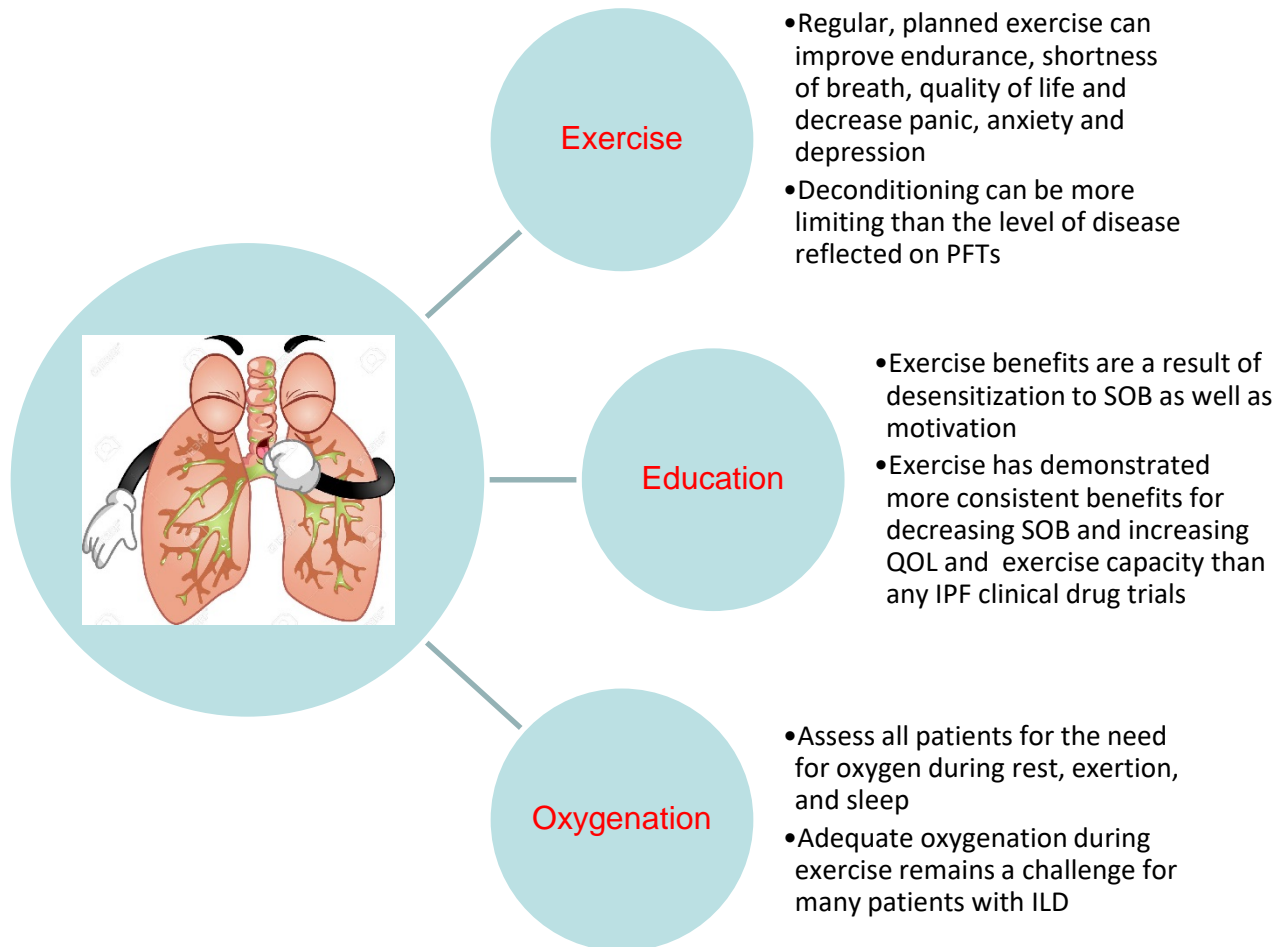
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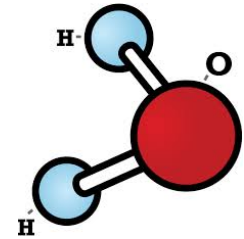


Dyspnea: Key Points

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Oxygen



- Prescribe for relief of hypoxemia, dyspnea, improved mobility and QOL, and improved survival
- Assess oxygen saturations at rest and exercise at regular intervals
- Provide pt. with written oxygen education materials, phone number to call if questions (1 800 MEDICARE), and discuss expectations
- Test patient in clinic and document in clinician notes:
 - Resting room air
 - Exertion room air
 - Exertion on oxygen and document liter flow needed to keep saturations above 90%
- Document in clinician notes:
 - lifetime need
 - delivery mode (nasal cannula)
 - use of pulse systems if OK
 - use of oxygen conserving device such as Oxymizer Pendant
 - specific device you are requesting (POC, liquid, etc...) and medical necessity/rationale

Liquid Oxygen

- Oxygen cooled down to liquid; able to provide larger amt. oxygen in smaller canister
- Delivers up to 10 L/min. cont. flow (different units for higher flow).
- Uses homefill system
- Higher costs of liquid:
 - More frequent delivery
 - Longer time to service
 - More customer needs



Refill from
reservoir

Liquid
Portable



Compressed Gas Oxygen:

E Tank:

compressed gas,
semi-portable, lasts 3
hrs. on 3L/min
continuous or 1.5 hrs
on 5 L/min



M6 (B) Tank:

compressed
gas, portable,
lasts with OCD
or OCR



Transfill Systems:

Homefill
I Fill
Ultra Fill



Portable Oxygen Concentrators: Size Matters!



- 3-20 lbs
- Uses battery; concentrates ambient air to 90-96% oxygen
- Can run off DC power
- FAA approved; need battery for 1.5 x hours of flight
- Higher liter flow = shorter battery life
- Very important to get tested on the system BEFORE you purchase it
- No continuous flow > setting of 3 or pulse flow over 6

Portable Oxygen Concentrators:

The Pulmonary Paper 'POC Annual Review' is a great resource for patients

www.pulmonarypaper.org

The Pulmonary Paper

Dedicated to Respiratory Health Care
May/June 2016 Vol. 27, No. 3

What POC is Best for Me?



Inside:
Our 2016 Annual Portable Oxygen Concentrator Guide

Oxygen Therapy for Interstitial Lung Disease: Physicians' Perceptions and Experiences

Yet H. Khor^{1,2,3,4}, Nicole S. L. Goh^{1,2,4}, Christine F. McDonald^{1,2,3}, and Anne E. Holland^{1,5,6}

- Aim: Explore perspectives of respiratory physicians about domiciliary oxygen therapy in ILD pts.
- Interviews of 25 Australian physicians
- Results:
 - Symptom relief was primary goal
 - Concerns raised regarding lack of clinical guidelines
 - Physicians perceived that ILD pts. were more compliant with DOT
 - Much variation with equipment, support, prescription
 - Main concern heard from patients = social stigma and sign of end-stage disease

Patient Perceptions of the Adequacy of Supplemental Oxygen Therapy

Results of the American Thoracic Society Nursing Assembly Oxygen Working Group Survey

Susan S. Jacobs¹, Kathleen O. Lindell², Eileen G. Collins³, Chris M. Garvey⁴, Carme Hernandez⁵, Sally McLaughlin⁶, Ann M. Schneidman⁷, and Paula M. Meek⁸

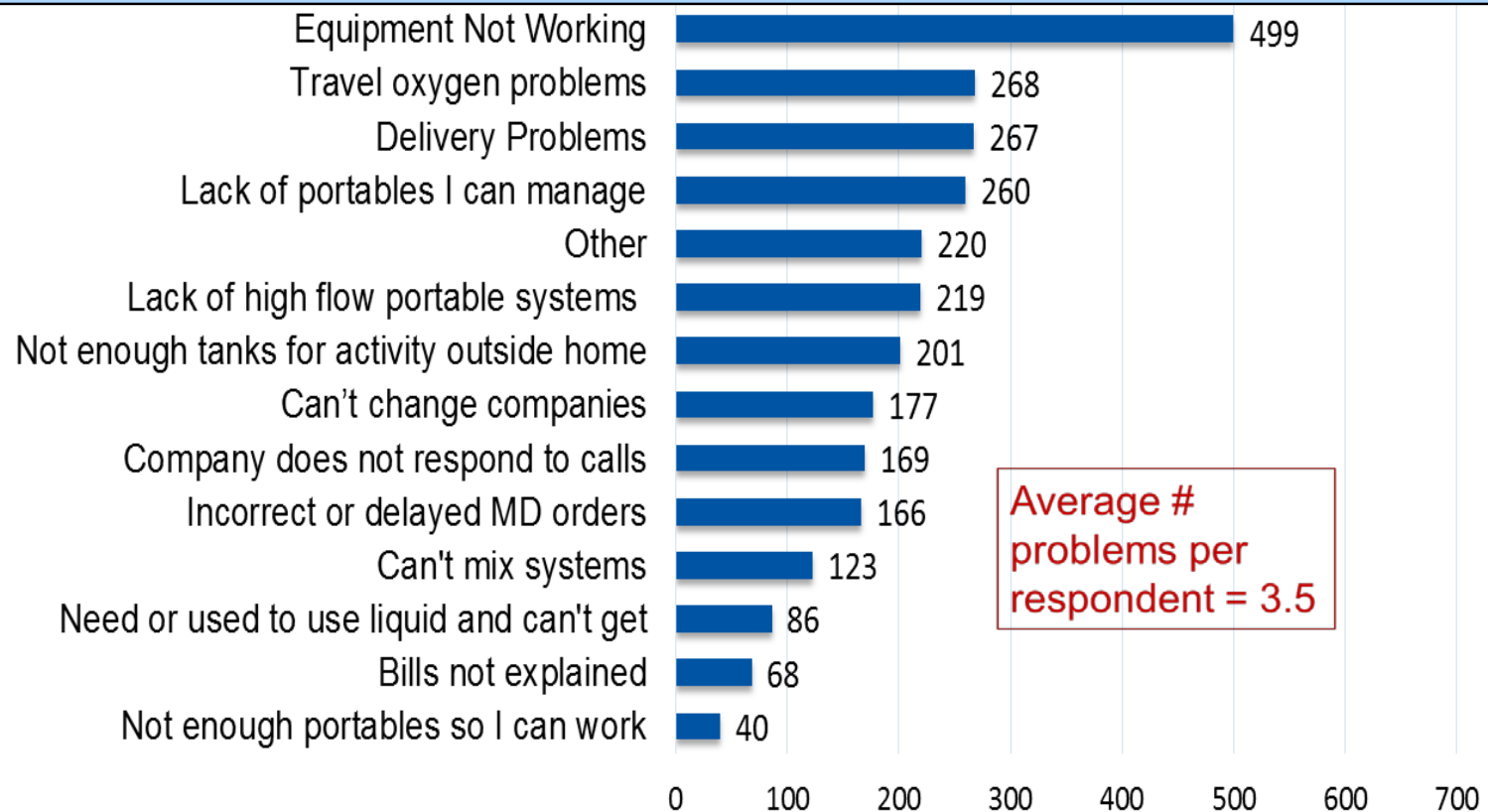
¹Division of Pulmonary and Critical Care Medicine, Department of Medicine, Stanford University, Stanford, California; ²Dorothy P. and Richard P. Simmons Center for Interstitial Lung Disease at University of Pittsburgh Medical Center, and Division of Pulmonary, Allergy and Critical Care Medicine, University of Pittsburgh, Pittsburgh, Pennsylvania; ³Biobehavioral Health Science, College of Nursing, University of Illinois/Research Service, Hines Veterans Affairs Hospital, Chicago, Illinois; ⁴Sleep Disorders and Pulmonary Rehabilitation, Department of Medicine, University of California–San Francisco, San Francisco, California; ⁵Integrated Care Unit, Hospital Clinic de Barcelona/University of Barcelona, Barcelona, Spain; ⁶Interstitial Lung Disease Clinic, University of California–San Francisco, San Francisco, California; ⁷Hospice of the Valley, Phoenix, Arizona; and ⁸College of Nursing, University of Colorado at Denver, Denver, Colorado

ORCID ID: 0000-0002-8808-0038 (S.S.J.).

Results: 51% of sample experienced problems with their oxygen

What types of oxygen problems do you have? (n=899)

(Able to select more than one choice)





Oxygen: Key Points



- Oxygen Rx is key turning point for patients
 - significant hallmark in a patient and family's disease trajectory
 - a cumbersome treatment.
 - pts. report problems with equipment, access and angst/concern/worry. (Lindell et al Am J Resp Crit Care Med 2017 A7646)
- Written and in-person oxygen education and equipment training by clinicians can mitigate some of these problems
- Provide pts. 1 800 MEDICARE to call with unresolved problems
- Medicare does not pay for travel oxygen; arrange FAR in advance with DME and MD; continued travel is important to the QOL of patients
- Test patients in clinic on the equipment they use at home

Isolation, Depression, Anxiety

- Support groups- in person, online
- Use of Social Worker in clinic
- Palliative Care Referral
- Address Caregiver needs



Isolation, Depression, Anxiety: Social Support

- Educational Seminar for patients and families offered by every other year by UCD, UCSF, and Stanford. Attendance between 200-300; next at UCSF, Mar/Apr 2019
- PFF Summit mtg. every other yr.- next in 2019 possibly Nashville

Stanford University Medical Center,
UC San Francisco Medical Center, and
UC Davis Medical Center Present:


Understanding Pulmonary Fibrosis


A Free Seminar for Patients,
Caregivers, and Families

WHAT
A free educational event featuring leading experts in lung disease who will address topics including diagnosis of pulmonary fibrosis, management issues, current and future research, lung transplantation, pulmonary rehabilitation, oxygen therapy, and available resources for patients and families.

WHEN
Saturday, March 7th, 2009 from 10am-2:30pm

WHERE
Frances C. Arrillaga Alumni Center,
326 Galvez St., at Stanford University (map on reverse)
Participants will be provided lunch and written educational materials.

 **STANFORD**
SCHOOL OF MEDICINE
Stanford University Medical Center

 **UCSF**
University of California
San Francisco

UCDAVIS
MEDICAL CENTER



Isolation, Depression, Anxiety: Social Support

➤ On line support groups

➤ www.rareconnect.org

➤ www.plmjoin.com/ipf

➤ www.pulmonaryfibrosis.org

➤ “PFF Voices”-Teleconnect Support Group- a call-in support group offered monthly by the PFF with guest speakers and a moderator

Isolation, Depression, Anxiety: Key Points

- Connect patients to resources!
- Support groups, pulmonary rehab, educational events
- Encourage travel, socialization
- Social worker, counseling as needed



Supportive Therapies for ILD Patients: Summary



Questions?



Susan Jacobs RN, MS (650) 725-8083 ssjpulm@stanford.edu