Table of Contents

Guest Editor for this issue:

Glenna Traiger, RN, MSN
Pulmonary & Critical Care
Pulmonary Hypertension CNS
University of California, Los Angeles
Los Angeles, California

Publisher
Pulmonary Hypertension Association
Carl Hicks, *Board Chair*
Rino Aldrighetti, *President*

Publishing Staff
Managing Editor
Deborah L. McBride
McBride Strategic Services
mcbridedeb@aol.com
Design Director
Michael McClain

PHA Office
Pulmonary Hypertension Association
801 Roeder Road., Ste 400
Silver Spring, MD 20910
301-565-3004, 301-565-3994 (fax)
www.PHAssociation.org

© 2010 by Pulmonary Hypertension Association. All rights reserved. None of the contents may be reproduced in any form whatsoever without the written permission of PHA.

Advances in Pulmonary Hypertension is circulated to cardiologists, pulmonologists, rheumatologists and other selected physicians by the Pulmonary Hypertension Association. The contents of the articles are independently determined by the Editor and the Editorial Advisory Board.

Cover Image
This issue's cover depicts the combined efforts of the multidisciplinary team of PH professionals working together to provide the best results for their patients.

Guest Editor's Memo

Living with PH: Longer and Better


Glenna Traiger, RN, MSN

Living with PH in the current era is complicated for patients and providers, but full of hope. Although we are still far from a cure, multiple FDA-approved medications, investigational agents, and advances in diagnostic techniques along with a greater understanding of disease mechanisms are helping patients live longer. In addition to increasing patients' length of life, the focus of the multidisciplinary PH team is to help patients live *better* by adapting to their illness and treatment regimens.

How should we assess patients' satisfaction with their lives? In this issue of *Advances in Pulmonary Hypertension*, Ann Gihl reviews the instruments that have been used to assess quality of life and the current literature on health-related quality of life in PH.

As in many other chronic diseases, depression may occur as a comorbid condition. Because of their close and longterm contact with PH patients, PH providers are well positioned to recognize depressive symptoms. Deborah McCollister and Dr Philippe Weintraub present a quick screening tool that can help us recognize depression and describe interventions to improve our patients' quality of life.

Once a treatment plan has been prescribed and implemented, patients must adhere to it. The patient must accept the therapy, feel that success is possible, and integrate it into their daily lives. Traci Stewart addresses barriers to medication adherence and interventions to improve adherence.

Targeted therapy for PAH has now been available for almost 15 years, allowing more and more of our pediatric patients to grow into adulthood. Michelle Ogawa and Darci Albrecht propose strategies to facilitate the transition of these patients from pediatric to adult care settings. *(continued on page 196)*

Editor's Memo


Richard N. Channick, MD

The invaluable role of non-physician members of the PAH care team has been impressed on me in recent months. Two months ago, after more than 20 years as a member of a successful team providing care to hundreds of PAH patients, I relocated across the country to start a new program at Massachusetts General Hospital. For a few weeks, I alone had to play all the parts in the play: answering calls, educating patients and hospital nurses on all aspects of PAH therapy, dealing with insurance companies, faxing prescriptions, following up on laboratory results, counseling referring physicians, adjusting medications, sorting through outside records, and even making my own coffee! As my (never again to be taken for granted) former nurse once said, "When it comes to the PH nurse/coordinator, there is no job description."

Simply stated, without dedicated PH nurses, respiratory therapists, and pharmacists, there would be no PH programs. There is so much more to PH care than ordering diagnostic tests and prescribing therapy. These patients have a complex chronic disease that causes profound effects that are both physical and emotional. Families are affected, quality of life is impacted, and the needs of these individuals are many.

The multidisciplinary aspects of a successful PH program cannot be overemphasized. When I speak with physicians around the country considering starting a PH program, the first thing I ask is "Will you have a dedicated PH staff?" Not uncommonly the response is "the hospital isn't willing to provide dedicated nursing and administrative support" or "if the program becomes busy enough, we may get a nurse." These sentiments virtually guarantee that a program will not succeed. The model of a robust, well staffed, knowledgeable, accessible PH program is well established. It works. Attend the upcoming International Pulmonary Hypertension Conference in June and you will understand.

The current issue of *Advances* represents a "first." All of us on the Editorial Board *(continued on page 196)*

Downloaded from https://prime-pdf-watermark.prime-prod.pubfactory.com/ at 2025-06-24 via free access

Advances in Pulmonary Hypertension Author Guidelines 2009

Scope of Manuscripts

Advances in Pulmonary Hypertension considers the following types of manuscripts for publication:

- Reviews that summarize and synthesize peer-reviewed literature to date on relevant topics in a scholarly fashion and format
- Letters to the Editor
- Clinical Case Studies

Manuscript Submission

Authors are required to submit their manuscripts in an electronic format, preferably by email to the Editor-in-Chief, Richard Channick, MD, rchannick@ucsd.edu. Please provide manuscripts in a word processing program. Images should be submitted electronically as well.

All material reproduced from previously published, copyrighted material should contain a full credit line acknowledging the original source. Authors are responsible for obtaining permission to reproduce such material.

Contact Information: List all authors, including mailing address, titles and affiliations, phone, fax, and email. Please note corresponding author.

Peer Review and Editing: Manuscripts will be peer reviewed. Accepted manuscripts will be edited for clarity, spelling, punctuation, grammar, and consistency with American Medical Association (AMA) style.

Manuscript Preparation

Length: Full-length manuscripts should not exceed 4,000 words, including references. Please limit the reference list to 50 citations. Manuscripts should be accompanied by figures and/or tables. Generally, 4 to 5 figures and 2 to 3 tables are preferred for each manuscript. Please include a brief description to accompany these items, as well as a key for all abbreviated words.

Spacing: One space after commas and periods. Manuscripts should be double spaced. Manuscripts should not contain an abstract but an introduction is recommended.

References: All submissions should include numbered references that are referred to in the text by superscripts and that conform to AMA style. Example: Lewczuk J, Piszko P, Jagas J, et al. Prognostic factors in medically treated patients with chronic pulmonary embolism. *Chest.* 2001;119:818-823.

Copyright: Manuscripts and accompanying material are accepted for exclusive publication in *Advances in Pulmonary Hypertension*. None of the contents may be reproduced without permission of the Pulmonary Hypertension Association. To request permission, please contact medical@phassociation.org

Guest Editor's Memo

(continued from inside front cover)

The roundtable discussion with panelists Karen Frutiger, Martha Kingman, and Abby Poms explores how allied healthcare professionals assist patients with the complex decisions to be made about PH treatment and care.

On behalf of the entire team of professionals dedicated to improving the lives of our PH patients, as guest editor of this issue my thanks go to Dr Channick and the *Advances* Editorial Board for giving us the opportunity to share our perspectives with you in the spirit of true multidisciplinary collaborative practice.

Glenna Traiger, RN, MSN
Guest Editor

Editor's Memo

(continued from inside front cover)

felt that it was important to devote an issue entirely to topics of particular importance to non-physician healthcare personnel. Although topics such as quality of life and psychosocial issues are part and parcel of comprehensive PAH care, we really wanted to provide a broad forum, beyond the "usual" strictly clinical scope of the journal. To that end, all of the contributions are from non-physicians. I think you will agree that the articles in this issue, while focusing on some non-medical areas, provide strong evidence-based information that will be of use to all readers. My thanks to Glenna Traiger for editing an outstanding issue.

And I actually do make my own coffee.

Richard N. Channick, MD
Editor-in-Chief

Downloaded from https://prime-pdf-watermark.prime-prod.pubfactory.com/ at 2025-06-24 via free access