

Research News Quarterly

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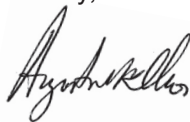
Letter from the Editor

Our second edition of the ATS Research News Quarterly features a new patient primer on research funding advocacy drafted by the Research Advocacy Committee with primary authors Marc Peters-Golden, M.D., Shannon Carson, M.D. and James Klinger, M.D. The primer, which is also available in pamphlet format for convenient distribution (contact nmoore@thoracic.org to receive it), provides useful facts and figures about lung diseases and research funding, including the current disparity in lung disease funding as compared to other major diseases, and issues a call to action for patients to rally in support of the NIH budget.

This month's Quarterly also features a report on the Capitol Hill welcome reception for NHLBI Director Gary Gibbons, M.D., attended by ATS President, Monica Kraft, M.D. and an update on NIH's plans to sustain and enhance the biomedical research workforce and improve its diversity through a number of new initiatives. These include a new grant program to support innovative research training strategies and an increase in the number of Pathway to Independence and Early Independence grant awards.

We also report on a new opportunity for patients, clinicians and researchers to become engaged in development of the patient-centered outcomes research agenda through membership on the Patient-Centered Outcomes Research Institute's (PCORI) Advisory Panels. And in our final article, our Washington Office staff makes sense for us of the ongoing budget battles in Washington, including the continued threat of across-the-board funding cuts to NIH. I would like to remind all ATS members that their continued advocacy is needed to protect U.S. research funding through NIH, CDC, EPA and the VA.

Sincerely,



Augustine Choi, M.D.
Editor

ATS Co-Hosts Capitol Hill Reception for NHLBI Director

In December 2012, the ATS co-hosted a reception on Capitol Hill with the National Heart, Lung and Blood Institute (NHLBI) Constituency Group to honor NHLBI Director Gary Gibbons, M.D. Dr. Gibbons was introduced by National Institutes of Health (NIH) Director Francis Collins, M.D., who lauded Dr. Gibbons for his energy and innovative leadership in guiding the institute since he became director in August 2012. Also in attendance was U.S. Surgeon General Regina Benjamin, M.D., who paid tribute to Dr. Gibbons for his work to advance public health at Morehouse College. In his remarks, Dr. Gibbons spoke of how he intends to use the same principles of advancing public health, with a special focus on reducing health disparities for racial and ethnic minorities, to guide NHLBI research efforts. Several members of Congress welcomed Dr. Gibbons, including COPD Caucus co-chair Sen. James Crapo (R-ID) and Representative Lois Capps (D-CA). The ATS was officially represented at the event by Monica Kraft, M.D., who said, “I was impressed both by Dr. Gibbons’ scientific vision in his comments and his ability to show how research impacts the daily lives of people.” ■



RESEARCH ADVOCACY

Research Funding for Respiratory and Critical Illness: A Primer for Patients

From the Research Advocacy Committee of the American Thoracic Society

Respiratory diseases have a huge human and economic cost in the U.S. and around the world. Research to improve diagnosis, prevention, and treatment of respiratory disease is essential to ease this burden, but it requires funding. Unfortunately, research for respiratory disorders in the U.S. is dramatically underfunded relative to their cost to patients and society. This article provides a brief overview of this issue and arms patients with the information they need to advocate for expanding investments in respiratory research.

Burden of Respiratory Conditions: Facts and Figures

Q. Of the 4 leading causes of death in the U.S., which is the only one whose death rates have risen over the last 30 years?

A. Death rates from heart disease, cancer, and stroke have all decreased by over 50%, while death rates from chronic obstructive pulmonary disease (COPD) have doubled over this interval.

Q. What is the leading reason for hospitalization among children in the U.S.?

A. Asthma is the most common chronic disease and the leading cause for hospitalization among American children.

Q. Besides having a baby, what is the leading reason for hospitalization among U.S. adults?

A. Pneumonia. In fact, around the world, respiratory infections are associated with more lost years of life and productivity than any other single category of

disease (including HIV infection, cancer, and heart diseases).

Q. What lung disease that most people have never heard of kills as many Americans each year as breast cancer?

A. Pulmonary fibrosis.

Q. What type of cancer is the leading cause of cancer death in the U.S. for both men and women?

A. Lung cancer.

Q. What critical illness kills as many Americans annually as do breast, colon, and prostate cancer combined?

A. ARDS, or acute respiratory distress syndrome, which occurs in response to severe infection and injury.

Research for Respiratory Disease: What Patients Should Know

As a patient with respiratory illness, you know how your disease affects you and the quality of your life. The facts and figures cited above indicate just how large a burden is attributable to lung disease. And although you are understandably focused on your own everyday treatment and needs, it is important to not lose sight of the fact that research is the key to future improvements in diagnosis, prevention, and treatment of diseases; it also has the potential to reduce health care costs in the future. Money spent on health care services does not fund biomedical research; rather, other funds must specifically be directed towards research.

The two major funders of biomedical research are drug companies (65% of total funding) and the federal government – primarily the National Institutes of Health (NIH) (30% of total funding); foundations and charities account for nearly 5% of total funding. Unfortunately, the lingering economic downturn and concerns about the deficit have frozen both government and corporate investment in biomedical research in recent years. For example, after adjusting for inflation, the NIH budget has actually decreased by almost 10% since 2003.

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Research Advocacy *(Continued from page 3)*

Only 2-3% of the total NIH budget – amounting to \$675 million annually – is allocated to respiratory-related research. Meanwhile, the total cost of lung disease in the U.S. in 2010 was estimated at \$186 billion. This means that the NIH spends less than one-third of a cent on research for every dollar that lung disease costs our country. How do these expenditures compare to those for other diseases? COPD is now the third leading cause of death in the U.S. and a major contributor to lost work, hospitalizations, and patient suffering. Yet for every research dollar allocated by the NIH for COPD, it allocates \$3.30 for stroke, \$16.67 for heart disease, and \$50 for cancer! Another analysis found that, of the 7 most underfunded diseases, 3 of them – COPD, pneumonia, and lung cancer – were lung diseases.

It is quite clear that decades of substantial investments in research in heart diseases and cancer have reduced their associated death rates – which is exactly the desired outcome of research. It seems obvious that reversing the rising death rates from COPD and other respiratory conditions requires that they be allocated their fair share of research investment.

Call for Action

Biomedical research is critical for reducing suffering and improving quality of life, reducing health care costs, and maintaining American competitiveness. Nevertheless, it rarely reaches the attention of the general public through newspapers and television and is usually ignored in national political discussions. Patients represent a powerful voice, and evidence shows that politicians listen to them. Death rates for lung diseases have increased while those for cancer and heart diseases have diminished. Success achieved in reducing deaths from cancer and heart disease is the result of substantial NIH funding for those diseases over the past thirty years. It is necessary that a similar emphasis in funding now be

directed towards respiratory and sleep disorders and critical illness.

Now that you are informed, there is a critical need for you to become more vocal about the importance of investing in respiratory-related research, which has been underfunded for a long time. You are undoubtedly familiar with advocacy groups for specific respiratory diseases, such as the Cystic Fibrosis Foundation and the Pulmonary Hypertension Association. These groups are doing important work to raise awareness of and promote research for their target diseases, and this must continue. However, it is also necessary to recognize that a more general investment in improving respiratory science and treatments will benefit all patients and those who care about pulmonary, sleep, and critical illness.

What Can You Do?

- Patients and health care providers can inform themselves about the importance of biomedical research – both generally and specifically related to respiratory disease.
- Individuals and advocacy groups must vigorously champion research funding in their local communities and at state and national levels.
- Raise awareness in your community of the need to support NIH research by writing letters to the editor in your local and regional newspapers.
- Contact your members of Congress to educate them about the vital importance of increasing overall funding for NIH as well as that dedicated to respiratory research.
- Sample letters and all of the information you need to contact your members of Congress can be found on the websites of the American Thoracic Society (<http://www.thoracic.org/advocacy/take-action-now.php>), Research!America (www.researchamerica.org/), or those of numerous specific disease advocacy groups. ■

AHRQ

AHRQ Director Announces Retirement

Agency for Healthcare Research and Quality (AHRQ) Director Carolyn Clancy, M.D., recently announced that she will retire after serving as Director of the agency for 10 years. Clancy, an internist and health services researcher, has led the agency's focus on healthcare quality and safety. She spearheaded the agency's first annual report to Congress on healthcare disparities and healthcare quality and led the development of the Affordable Care Act's National Quality Strategy. Dr. Clancy will remain Director of AHRQ until a successor has been named. ■

RESEARCH WORKFORCE

NIH Unveils Plans to Foster Biomedical Research Workforce

Following on the release of working group reports on the diversity and sustainability of the biomedical research workforce, the NIH has announced a number of proposed new initiatives to help strengthen the research workforce and achieve greater diversity.

In a report released last year, the Workgroup on the Biomedical Research Workforce analyzed data on the state of the research workforce and found that there are a number of factors that have made starting a traditional academic research career more difficult. These factors include a significant increase in both US-trained and foreign postdoctoral fellows, an aging of the academic scientific workforce, and long training and lower

early-career salaries as compared to other scientific disciplines.

In response to these findings, the workgroup issued a series of recommendations to improve graduate, postdoctoral and physician scientist training. To improve postdoctoral training, the panel called for a shortening of training time, increased support for training grants and fellowships and improvement of pay and benefits. The workgroup found that the economic and educational drivers are significantly different for physician scientist training than they are from PHD training and career paths. The panel concluded that in order to make appropriate recommendations more time is needed to study these aspects of physician researcher training and called for a follow-on study to analyze the current composition and size of the physician researcher workforce, assess present and future needs and identify incentives and barriers to physicians entering and continuing research careers, including medical education costs. The workgroup also recommended that the NIH develop a long-term plan to address NIH-provided faculty salary support.

The NIH's Advisory Committee to the Director reviewed the workgroup's recommendations and in December 2012 proposed the following new initiatives to implement the workforce workgroup's recommendations:

- Creation of a new grants program to support innovative approaches to complement traditional research training at NIH-supported institutions
- Increase initial postdoctoral researcher stipends and work to create a national benefit package standard
- Increase the number of Pathway to Independence K99/R00 and Early Independence Awards
- Encourage the adoption of individual development plans for all trainees.
- Identify and track more accurately all NIH-supported graduate students and postdoctoral researchers to provide to enable better assessment of workforce needs

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Research Workforce *(Continued from page 5)*

The Advisory Committee to the Director's Workgroup on Diversity in the Biomedical Research Workforce is proposing the following initiatives to increase diversity:

- Creation of a new program called Building Infrastructure Leading to Diversity (BUILD) to provide robust mentoring for undergraduate students; funding support for biomedical research careers and faculty support for mentor training
- Launch a National Research Mentoring Network to connect students, postdoctoral fellows, and faculty with experienced mentors and provide workshops and training opportunities in grantsmanship
- Establish a new chief diversity officer position to coordinate NIH diversity programs
- Create an NIH-wide steering committee workgroup on diversity

The timeframe for implementation of these initiatives is not yet clear as they are still undergoing review by the NIH leadership. The ATS will continue to monitor the NIH's efforts to sustain the biomedical research workforce and increase its diversity. ■

PATIENT-CENTERED OUTCOMES RESEARCH

PCORI Seeks Members for Four Advisory Panels

The Patient-Centered Outcomes Research Institute (PCORI), an independent institute set up under the Affordable Care Act to conduct patient-centered outcomes research, is inviting applications for members on its four advisory panels. Membership is open to patients, clinicians, researchers and the general public on the following panels:

- Advisory Panel on Addressing Disparities
- Advisory Panel on Assessment of Prevention, Diagnosis, and Treatment Options.
- Advisory Panel on Improving Healthcare Systems
- Advisory Panel on Patient Engagement

Although advisory panel members do not serve in an official decision-making capacity, panel members will provide recommendations to the PCORI Board of Governors, Methodology Committee, and staff to help plan, develop, implement, improve, and refine the patient-centered outcomes research agenda. Each advisory panel will have twelve to twenty-one members depending on its charter. For more information, including charters for each of the advisory panels and how to apply, visit the PCORI website at: <http://www.pcori.org>. Applications are due by March 4, 2013. ■

RESEARCH FUNDING

Fiscal Cliff and Sequestration Temporarily Averted

In early January, the House, Senate and the President reached agreement on a bill averting the "fiscal cliff" of expiring tax cuts, the Medicare physician payment cut and budget sequestration funding cuts to federal agencies. The President signed the bill into law after the House passed the measure by a vote of 257 to 167. The bill addressed two key issues for the ATS – across-the-board sequestration funding cuts to most federal agencies and a 27 percent Medicare physician payment cut. Under the deal, sequestration funding cuts will be postponed for two months until March 1 – setting up another short deadline for Congress and the President to address deficit control. The bill also enacts a temporary one-year fix update of 0.0% to the Medicare

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Research Funding *(Continued from page 5)*

physician payment formula, which will keep payments at current rates.

There is also some good news arising out of an agreement made this month on raising the debt ceiling, which had originally been scheduled to expire on March 1, at the same time as budget sequestration implementation. The debt ceiling increase has made more funding available for FY2013, which will reduce the size of the sequestration cuts, from 8.2 percent down to an estimated 5.1 percent. Although the reduction in the size of the cut minimizes the damage somewhat, an across-the-board cut of over 5 percent will still have a significant effect on the NIH because if implemented, the cuts will occur in the middle of the fiscal year, forcing researchers to immediately absorb a large cut out of planned funding allocations. In a recent interview, NIH Director Francis Collins, M.D., Ph.D., described the impact of sequestration as a “profound and devastating” blow at a time of unprecedented scientific opportunity.

As the March 1 deadline for the implementation of sequestration funding cuts is drawing closer, it is

unclear whether the cuts will actually be implemented on March 1 or postponed yet again. Although the postponement of sequestration is a welcome relief for agencies such as the NIH, CDC and EPA, all of which would have struggled to implement across-the-board cuts to all programs, the difficult issue of sequestration has been passed on to the new 113th Congress. The President has indicated that he wants a new deficit control deal that balances spending cuts with revenue increases, but Republicans are stating that sequestration funding cuts remain on the table. Another key issue to be resolved by the new Congress by March 31 is finalization of fiscal year 2013 funding levels for all federal programs.

The ATS will work to protect the NIH, CDC, EPA and USAID from funding cuts and urges members to continue to educate their members of Congress about the need to prioritize our research, global public health and environmental protection agencies. ATS member advocacy throughout all states is critical to protecting the NIH budget. ■