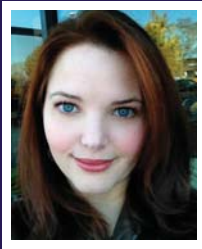




"2012 was an important year for the RPF as it solidified its position as a vital and definitive voice for rheumatoid patients. Beyond educating patients and providing support, the RPF has taken important steps toward providing feedback and information for clinicians, researchers, and the pharmaceutical industry about the experience of rheumatoid patients."



feedback and information for clinicians, researchers, and the

pharmaceutical industry about the experience of rheumatoid patients."

-- Shannon Ragland, RPF Volunteer

Welcome to our first annual report. We will attempt to provide a brief summary of an entire year of *elevating the patient voice*. From the photographs that patients donate for our literature to the survey questions that they answer, patient participation is our primary approach to realizing our mission.



Last year, we impacted patients' lives by contributing via several spheres:

- We presented to the public a more accurate and complete picture of rheumatoid disease as patients experience it.
- We provided educational and advocacy resources for rheumatoid patients and those who care for them.
- We engaged media, research, government, and industry, carrying the patient experience to those who have opportunities to impact our care.

No list of programs or financial pie charts can capture an entire year of inspiration and change. We are honored to bring the voice of rheumatoid patients to the healthcare world and take one step closer to a time where no one suffers from rheumatoid disease.

There's so much to share with you, so let's get started.

Sincerely,  
Kelly Young, RPF Founder

## **VISION:** *Our vision is a world where no one suffers from rheumatoid disease.*

**Our values – Every day, these guiding principles serve as a compass for our board and staff.**



**Teamwork with patients** – We recognize patients as essential partners in efforts of scientific discovery, disease education, and awareness.

**Quality** – We work towards excellence in fulfilling our mission to improve the lives of people with rheumatoid disease.

**Commitment** – We are passionate in our dedication to see a world where no one suffers from rheumatoid disease.

**Leadership** – We are leaders in the fight against rheumatoid disease. Through hard work and creativity, we provide accurate information about the disease, promote support and quality care for patients, stimulate increased scientific discovery, and advocate for favorable policies.

**Integrity** – We are honest and straightforward, treating all with dignity and respect. We act responsibly with resources entrusted to us.

# MISSION: RPF is dedicated to improving the lives of people with rheumatoid disease.



## EDUCATION PROGRAMS

The RPF creates materials to educate about the disease commonly called RA or Rheumatoid Arthritis. Our materials can help educate patients about what to expect from the disease and its treatments. Educated patients are better able to participate in treatment decisions and manage this lifelong condition.

This year, components of the education program included the creation of printed materials, website resources, medical event exhibits, as well as distribution of those materials.



**Brochures** – RPF printed various tri-fold and quad-fold brochures containing thorough, concise, and clear information about the disease and issues related to it.

**Posters** – RPF produced two original posters summarizing results of large online surveys about patient experiences.

**Awareness Card** – RPF created a business card sized tool to educate about rheumatoid disease. This resource is available to order pre-printed or to download and self-print.

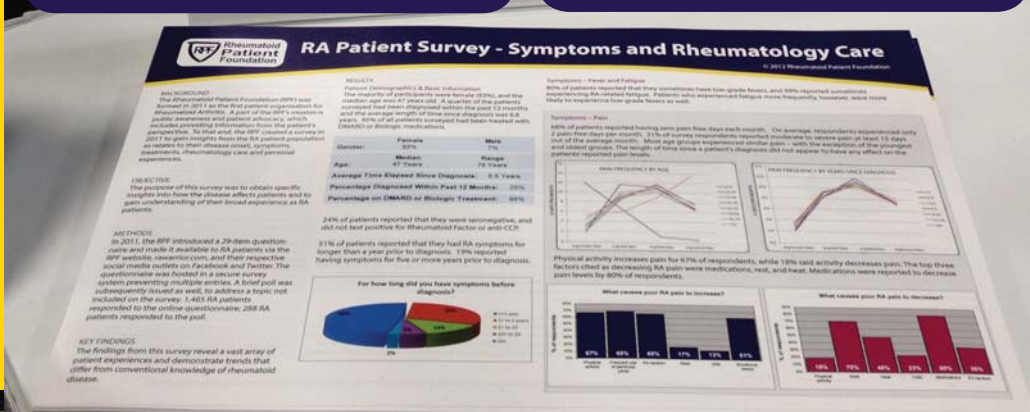
“Exhibiting at ACR gave us a chance to increase awareness of the RPF and its mission, share our resources and patient survey findings, and make connections with rheumatologists and others in the industry.”

-- Dana Symons, RPF Board Member

RPF at the American College of Rheumatology, 2012 Annual Scientific Meeting

**Website** – RPF built a website expanding basic disease information, providing a member forum, and multiple resources for the public such as infographics and banners.

**Survey** – RPF provided opportunities for patients to inform the public and healthcare professionals about their own condition and ways the disease affects their lives.

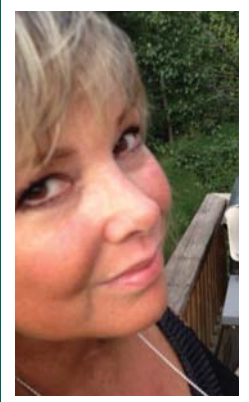


**Exhibits** – RPF exhibited at three events in 2012, allowing the opportunity to educate patients, preparing them to make decisions for better care; and to educate others involved in healthcare about the rheumatoid patient perspective, which has potential to improve patient care by improving communication and fostering a patient-centric point of view.

1. Arthritis Introspective Annual Gathering
2. Rheumatology Nurses Society Annual Meeting
3. American College of Rheumatology Annual Scientific Meeting



# OUR GOALS: AWARENESS, SUPPORT, ADVOCACY, CURE



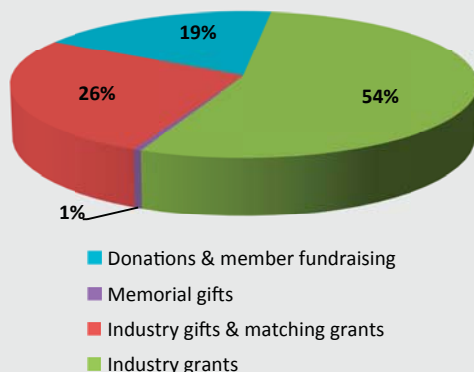
"Thank you RPF...for the education you are doing in the general public. This

site shows me that I'm not alone in my daily struggles."

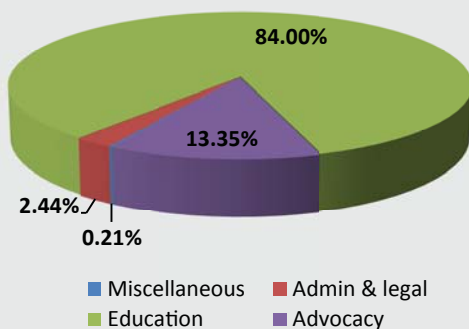
-- Janette L. Sands, RPF Member

## 2012 Income & Expenditures

2012 Sources of Support



2012 Expenditures by Program



## AWARENESS & ADVOCACY PROGRAMS

- 1. Membership** – Affords additional opportunities for input from many patients, helps equip members to advocate for themselves and others, and extends the influence of RPF.
- 2. Rheumatoid Awareness Day** – RPF planned for the establishment and launch of the first day set aside specifically for rheumatoid disease awareness, held February 2, 2013.
- 3. Social media, website, and graphics** – RPF provides written and visual materials via [rheum4us.org](http://rheum4us.org) pages and social media accounts to promote awareness.
- 4. Store** – Creating and selling items for purchase featuring awareness ribbons, RPF logo images, or other educational images related to rheumatoid disease (implemented 2013).
- 5. Testimony at FDA** – Presentation to U.S.F.D.A. Arthritis Advisory Committee to inform committee of the unmet needs in rheumatoid patients and the crucial necessity of new treatments.
- 6. Capitol Hill Advocacy** – Contributing to discussions with representatives in various offices to ensure the rheumatoid patient needs are heard, including FDA, HHS ONC HIT, PCORI, the White House, and Congressional offices.



"I am grateful for the chats, forum and social presence that the Rheumatoid Patient Foundation has provided for patients. RPF gives me hope for a cure for this disease in our future."

-- Tanya Martin, RPF Member

# HOW YOU CAN HELP

**RPF needs your help to continue to serve rheumatoid patients and those who care for them. With your help, we will continue to elevate the patient voice and improve the lives of people touched by rheumatoid disease.**

## **BOARD OF DIRECTORS:**

Barbara Cloues  
Dana Symons  
David Biundo  
Jay Sprinkel  
Kelly Young  
Nancy Murphy (leave of absence)

## **ADVISORY BOARD:**

Rebecca A. Bader, PhD – Professor,  
Syracuse University

Clifton O. Bingham, III, MD – Johns  
Hopkins Rheumatology

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Clinical Immunology & Rheumatology  
at University of Alabama

John M. Davis, III, MD – Mayo Clinic  
Rheumatology

Dave deBronkart – Author, cancer  
survivor, public speaker, and policy  
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Lisa Emrich – Writer for Health Central  
and Brass and Ivory

Carla Jones – Author of Death by  
Rheumatoid Arthritis and speaker

Charles M. King II, MD – North  
Mississippi Medical Center,  
Rheumatology

Kevin Purcell – President of Arthritis  
Introspective

Yusuf Yazici, MD – New York University  
Hospital for Joint Diseases

Roni Zeiger, MD - CEO Impatient  
Science, practicing physician

## **1 Contribute**

- **Make a Donation**
- **Add RPF to Your Will**
- **Donate Your Photos or Videos for use by RPF**
- **Contribute to Our Scholarship Fund**

## **2 Get Involved**

- **Become a Member**
- **Volunteer Your Time**
- **Organize a Fundraiser**
- **Purchase Awareness Gear**
- **Share RPF Educational & Awareness Resources**

## **3 Learn More at [rheum4us.org](http://rheum4us.org)**



“RPF provides an important face and voice of people who live with rheumatoid disease. By emphasizing the consequences of the disease on multiple aspects of quality of life and abilities to participate in valued life activities, and by providing timely, topical, and accessible information, RPF is serving an important role in immediately helping people diagnosed and living with this condition, and in increasing public awareness of RA and its impact.”

– Clifton O. Bingham III, MD , Johns Hopkins Rheumatology,  
RPF Advisory Board Member



**Rheumatoid  
Patient  
Foundation**

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Cocoa, FL 32923  
<http://rheum4us.org>