



**Rheumatoid  
Patient  
Foundation**

## 2013 Annual Report

### *Bringing Rheumatoid Disease out of the Shadows*

"With the inaugural Rheumatoid Awareness Day, groundbreaking patient-led research, advocacy efforts and educational opportunities, 2013 was a banner year for RPF. While there is much work yet to be done, we hit several important milestones this year that will be a springboard to provide momentum going forward."

-- Dana Symons,  
Vice President



Welcome to the 2013 annual report for the Rheumatoid Patient Foundation. Here you will find a summary of a year's worth of *Bringing Rheumatoid Disease out of the Shadows*. Consider just a few of the ways we've impacted the lives of patients and families living with rheumatoid disease:



- We brought to light the true nature of rheumatoid disease through the establishment of February 2nd as Rheumatoid Awareness Day.
- We created additional educational resources and made them available to health professionals in their offices and to our members online.
- We provided new advocacy tools to help people with rheumatoid disease better advocate for themselves and for others.
- We published novel research, bringing the voice of patients to health professionals to encourage improved doctor-patient partnership.

Thank you for your part in RPF. Together, we continue to improve the lives of people affected by rheumatoid disease.

Sincerely,

Kelly Young, RPF Founder

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

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

**OUR GOALS:** **AWARENESS, SUPPORT,  
ADVOCACY, CURE**

# ADVOCACY & AWARENESS PROGRAMS

## Rheumatoid Awareness Day

In 2013, RPF established February 2nd as Rheumatoid Awareness Day, providing a special day of recognition for rheumatoid disease. Components and highlights of the inaugural Rheumatoid Awareness Day campaign included:

- Two press releases, distributed on the national wire and picked up in many local markets
- A Facebook Event with over 8,000 worldwide participants
- Awareness information and resources with over 6,500 shares on social media
- A Facebook chat, generating over 250 comments in an hour
- Twitter conversations centered around the hashtag #rheum generated 3.7 Million impressions
- \$16,000 raised through individual donations, memberships and a matching donation from Crescendo Bioscience



Thousands of patients banded together for this momentous occasion, and many people took the initiative to celebrate in their own way by organizing local patient meetups, sporting our indigo and gold colors, meeting with their local government representatives to get official proclamations for Rheumatoid Awareness Day, and more. We believe that Rheumatoid Awareness Day will be a great foundation to build awareness and promote education going forward.

## RPF Members Raise Awareness of Rheumatoid Disease & Over \$4,000 to Support RPF

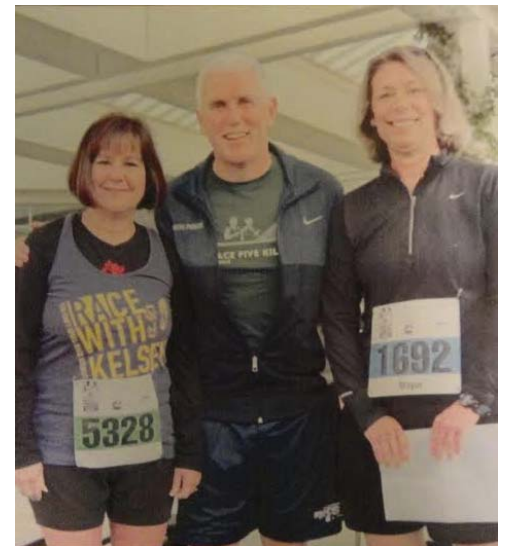
RPF would like to thank its members for working hard on various kinds of fundraising events in 2013. One notable example was the annual Mill Race/Half Marathon/5k team organized by Kim Pence in honor of her daughter, Kelsey Pence Russo, in Columbus, IN. Through this event, Kelsey (an RD patient) accomplished a personal goal by completing a half marathon and also raised significant awareness of Rheumatoid Disease and over \$4,000 in support for RPF.



Organizers & RPF members Kelsey Pence Russo, & Kim Pence



Race participants show their support



Mrs. Karen Pence, Governor Mike Pence, and Mayor Kristen Brown (of Columbus, IN) at the race

## Advocacy Resources

RPF added a section on Rheumatoid Disease Advocacy to its website, featuring tips, tools and resources from several members who have been involved in advocacy initiatives. This information is intended to be used as a reference and starting point for anyone who is interested in participating in patient advocacy with the help of RPF. Rheumatoid Awareness Day inspired several RPF volunteers to do some great advocacy work within their local areas!

**"To help support Rheumatoid Awareness Day, I have started a campaign to have the local city councils in my area officially acknowledge February 2nd as Rheumatoid Awareness Day. It is my hope to present these requests in person at various council meetings in my area, providing another opportunity to educate, inform, and recruit supporters." --Jeanie Ready, RPF Member**

# RESEARCH & EDUCATION PROGRAMS

## American College of Rheumatology

### Published Research

RPF has conducted several research surveys over the past couple years, which our members and constituents have participated in. Using findings from two different surveys, RPF submitted two research abstracts to ACR. Both abstracts were accepted by ACR for poster presentations and publication in a supplement of the October issue of *Arthritis & Rheumatism*, an official journal of the American College of Rheumatology. The research findings were presented by Kelly Young and abstract co-authors (Dana Symons, VP; Andrew Lumpe, Member; and Cynthia Crowson of Mayo Clinic) in the Poster Hall during the ACR Annual Meeting.

Findings presented included data on disparities that exist between current medical literature and actual experiences of those living with rheumatoid disease – including the concept of “morning stiffness,” the relationship between swelling and joint damage, and factors that increase or decrease symptoms. Additional data was presented examining how the Health Assessment Questionnaire (HAQ) gauges fundamental aspects of rheumatoid disease, including the consequences of physical activity as seen in a real-world context.

### ACR Exhibit

In 2013, RPF participated as an Exhibitor at the American College of Rheumatology (ACR) Annual Scientific Meeting for the third time. We had a booth space in the Exhibit Hall where several RPF volunteers from around the United States were able to interact with rheumatologists and other health professionals. This gave us the chance to increase awareness of RPF and its mission, to form connections and build relationships with doctors, researchers and other industry professionals, and to share our own educational materials. We had a wonderful group of volunteers who did an amazing job representing RPF at this major event, which draws in over 10,000 rheumatology professionals from around the world.

### Educational Session

RPF broke new ground by having our own speaking session at the 2013 ACR Annual Meeting. RPF Founder and President, Kelly Young, Dr. Jeffrey Curtis (rheumatologist and RPF advisory board member), and Dr. Elizabeth Riggs, PhD (registered nurse, RD patient, and RPF member) participated in a combined speaking session on Patient Engagement. The room was packed full of rheumatologists and health professionals interested in this topic. The speakers did a dynamic job discussing ways to incorporate patient reported outcomes, overcome obstacles to shared decision making and engage patients as partners. The entire audience was engaged and the session was very well received among the attendees.

**“I want you all to know that this session was one of the most meaningful and memorable sessions I have ever attended. I can say that because each of you shared your personal stories and experiences about this dreadful disease, I will be a better provider. I will listen longer, talk slower, work harder, and partner with patients more than ever.”**

-- Dr. Charles King, MD, RPF Advisory Board Member





# EDUCATION PROGRAMS

## Publications & Print Materials

### Educational Brochures

The RPF creates materials to educate patients, health professionals and others about rheumatoid disease. Educational materials are available for health professionals to order from the RPF website. Our educational brochures have already been placed at a number of rheumatology offices and medical clinics across the United States. Previews of all of our educational materials are available on the RPF website, and full-sized printable versions are available to Members. RPF also includes brochures in its new member kits.

In 2013, RPF introduced two new brochures:



#### Treat to Target in Rheumatoid Disease

Tri-fold, informational brochure outlining the concept and benefits of Treat to Target, particularly for rheumatoid patients. This brochure discusses disease activity (DA), measures of DA and T2T goals.

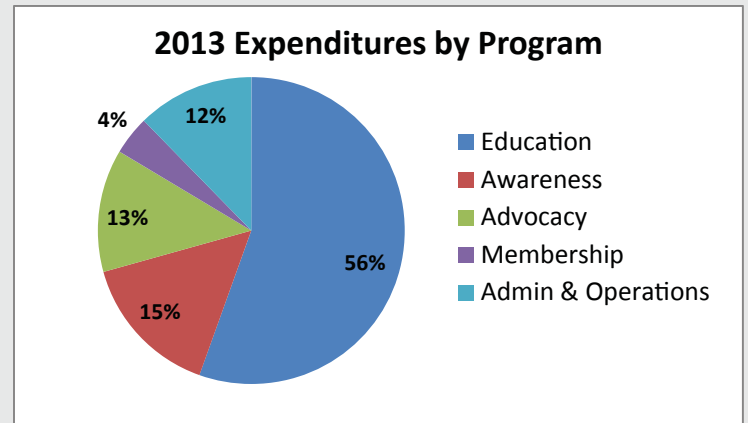
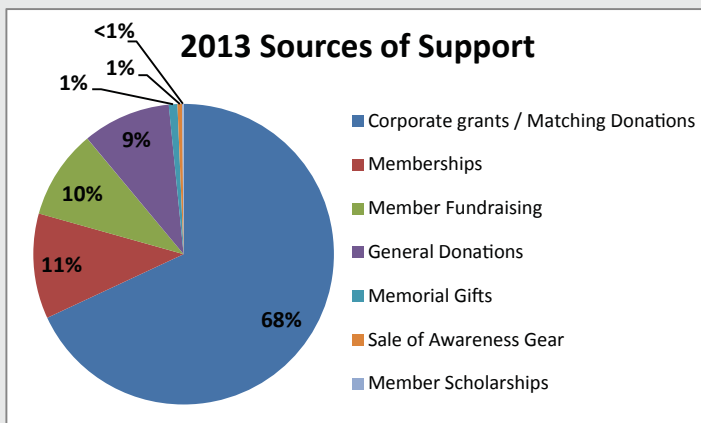
#### Methotrexate: The Most Prescribed Treatment for Rheumatoid Disease

Tri-fold, informational brochure providing basic information about methotrexate, as used to treat Rheumatoid Disease. This brochure also includes common side effects and strategies for managing them, as well as answers to frequently asked questions. Ideal for those considering MTX or who recently began taking MTX to treat RD.



**A**t ACR, I saw firsthand the amazing things that the Rheumatoid Patient Foundation has accomplished, so far! It was empowering and helped me realize that so many others really do understand and care about our pain and struggles. We are not alone and there really is hope! --Norma Martinez, RPF Member & Volunteer

## 2013 Income & Expenditures



# HOW YOU CAN HELP

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RPF needs your help to continue to serve rheumatoid patients and those who care for them. With your help, we will continue to increase awareness, to bring rheumatoid disease out of the shadows, and to improve the lives of people touched by rheumatoid disease.



## 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)

“Love that the truth about RA is getting out there; so much misinformation out there! It isn't about ‘aches and pains’!”  
--Merri Lewis



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