



# ...A YEAR IN REVIEW

DEAR SUPPORTERS,

2012 has been a year of expanded communications and outreach for the Spondylitis Association of America. Our efforts to educate specialty doctors, including chiropractors and primary and family care physicians were ramped up this past year. Moreover, we have expanded our partnership and collaborative efforts with consumer, commercial, public and private-sector health organizations that help us pursue our mission. Our website continues to serve and to educate tens of thousands of individuals per month; social media outreach supports thousands of individuals in direct correlation with an expansion of individual fundraising on our behalf.

Indeed, we have deepened our commitment to research with a newly focused approach that includes the initiation of a Spondyloarthritis Patient Registry and a partnership with the American College of Rheumatology to develop much needed Treatment Guidelines in spondyloarthritis.

In advocacy we have been working closely with other mission driven organizations, which has resulted in our lawmakers voting to extend funding for arthritis and joint disease research.

The Spondylitis Association of America is the only organization that solely supports individuals affected by spondyloarthritis, who turn to us for information, support and opportunities to be heard. We listen and we act upon what we hear.

Our goal is to be bold, to work hard and to make a difference. We are here to serve. We are proud of our successes but our challenges - reaching those who are still suffering — are what drive us to work harder and do more every day. It is our responsibility to remain fiscally robust in order to achieve these goals.

More than ever, we are grateful for your ongoing encouragement and support.

Thank you.

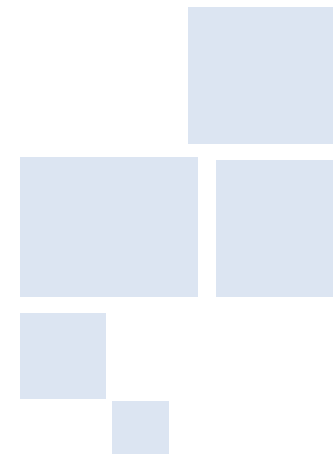
Sincerely,



Laurie Savage, MS FLE, Executive Director



Craig Gimbel, DDS, Board Chair



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# RESEARCH



SAA established its annual Bruckel Young Investigator Award, which recognizes outstanding "contributions to the care and understanding of patients with spondyloarthritis." The award winner receives a \$10,000 grant from SAA for use in spondyloarthritis research. Pictured is Dr. Judith Anne Smith, the first winner of the Young Investigator Award for her work on macrophages and the inflammatory process in AS.

2012 marked the release of the first ever epidemiology study conducted by the CDC in the US, and supported by the SAA and by SPARTAN. The CDC researchers used the data and statistical methodology from the SAA Screening Tool for Ankylosing Spondylitis as a foundation for the patient questionnaire that was developed by the CDC for the 2009/2010 study. To date, manuscripts authored by the CDC researchers, Drs. Reville and Weisman have been accepted for publication by JAMA and by Arthritis and Research, the ACR peer review journal. Additional manuscripts are forthcoming.





The Triple-A (Australo-Anglo-American) Spondyloarthritis Consortium, or TASC, has identified 20-plus new genes linked to ankylosing spondylitis since 2007. In the future, these genes can lead to new treatments and possibly earlier diagnosis. SAA originally ignited spondylitis genetic research in the US and continues to participate in the ongoing TASC study by encouraging enrollment.

In 2012, phase one of a Patient Registry for Ankylosing Spondylitis was completed. Funded initially by SAA, the patient registry is a database - a compilation of data on people with ankylosing spondylitis. In this case, the registry is a combination of three current patient databases that have been used in ankylosing spondylitis research. The patient registry will enable us to look at thousands and potentially tens of thousands of patients with AS and see health trends, disease severity over time, age, medication effectiveness, complications and more.





# SAA PROGRAMS:

## Help You Connect in Person...

"Thanks for the great work all of you do, and the wealth of invaluable information you provide!!! I am glad to be a member."

~Sandra



### *SAA Sponsored Educational Support Groups*

"Thank you so much for your hospitality, kindness, and leadership in getting us all together. I met some amazing individuals and got to learn so much from all of you. Really appreciate it." ~Sue, Philadelphia Educational Support Group

### *Patient Educational Seminars*

"So glad I came. Learned more here than on my searches or from my doctor. Thanks!" ~ Nashville, TN Seminar Attendee

## Provide Support & Education Online...

### *Spondylitis.org & SWIFT - Spondylitis Web Info For Teens - [teens.spondylitis.org](http://teens.spondylitis.org)*

"Thank you for everything that you are doing for the spondylitis community and to educate people about this disease." ~Jen

### *SAA Message Boards & Communities on Facebook, YouTube & Twitter*

"Reading as much info as I can absorb today; it was like reading my autobiography. Thanks so much in advance. Very excited to find this Facebook site!" ~Jennifer



"So happy there is this resource (SAA) to help me live a better life."

~Suzette



## Bring You the Latest News & Information...

### *eSUN - the electronic Spondylitis Update Newsletter*

"Your eSUN updates on the latest research in AS are great. Keep them coming." ~Clarke

### *Online News & Publications*

"SAA publications have been a great help to me, as has been my local support group. Thanks." ~Marion



## And Do So Much More.

### *Toll free info line, Advocacy & Professional Education...*

"Thank you SAA - we are so grateful that you have our 'backs'! I'd be a wreck without the support, education, awareness, research, testimonials and new friendships I've made! THANK YOU!" ~Tanya

# DEVELOPMENT, MEMBERSHIP & FUNDRAISING

In FY12 the Spondylitis Association was awarded the coveted 4-star rating from Charity Navigator for sound fiscal management and a proven commitment to accountability and transparency. This is the fourth consecutive year SAA has earned this top distinction. Only six percent of the charities rated by Charity Navigator have received at least four consecutive 4-star evaluations. This “exceptional” designation differentiates us from our peers and demonstrates to the public that we are worthy of their trust.

Charity Navigator, America's largest and most-utilized independent evaluator of charities, works to help charitable givers make intelligent giving decisions by providing information on more than five thousand charities nationwide and by evaluating their financial health. It calculates each charity's score based upon several broad criteria, including how much is spent per dollar raised, what percentage of funds goes to programs versus administrative and fund raising expenses, and the organization's long-term financial health. It then assigns a rating from one to four, with four being the best rating.



As the nonprofit sector continues to grow at an unprecedented pace, savvy donors are demanding more accountability, transparency, and quantifiable results from the charities they choose to support with their hard-earned dollars. Receiving the highest possible rating from Charity Navigator illustrates our commitment to good governance and highlights how we pursue our mission in a fiscally responsible way.

“Thank you all at SAA, for your continued excellence and for being a source of information. This 4-Star Charity is working to find a cure for AS and that's why I've been a proud member for at least 10 years. Thank you from the bottom of my heart. You give me hope.”

~ Lisa



# "SAA Rocks"

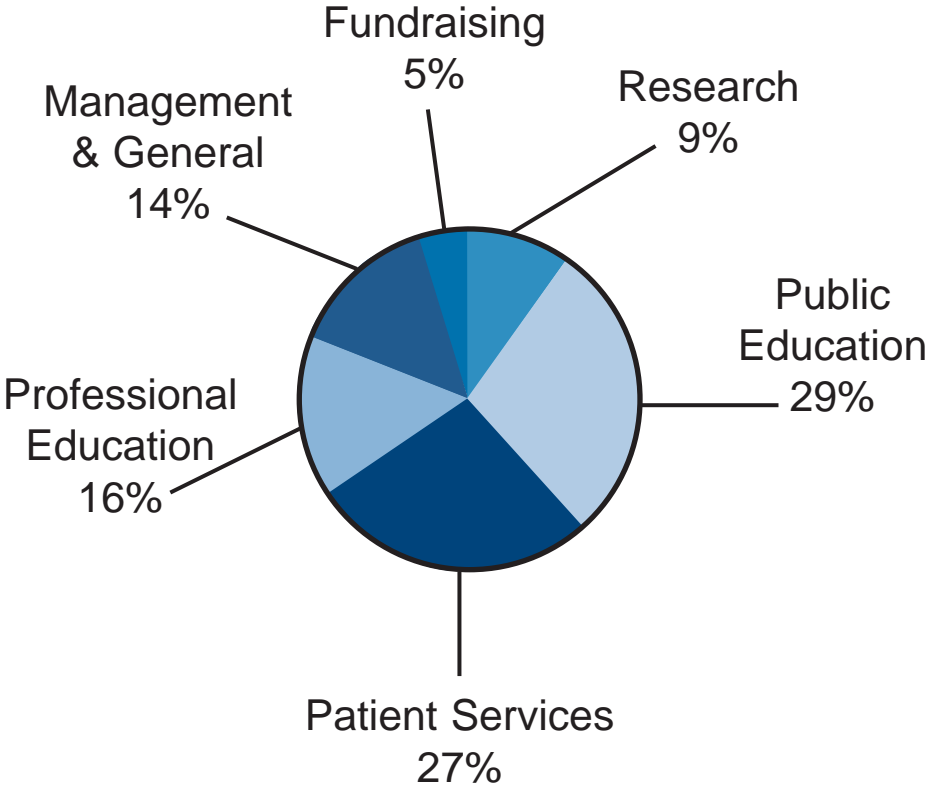
~ John



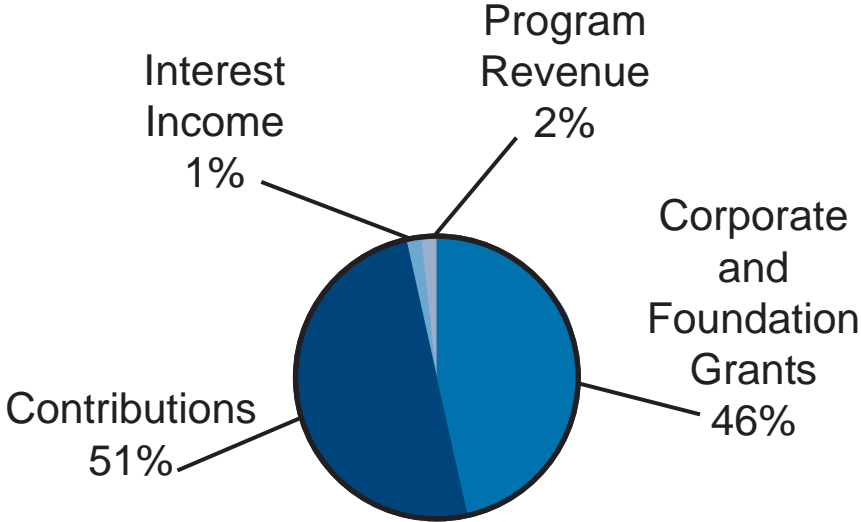


# FINANCIALS

## FY 2012 EXPENSES



## FY 2012 REVENUE



# STATEMENT OF FINANCIAL POSITION

YEAR ENDED JUNE 30, 2012



<b>Assets</b>	<b>2012</b>	<b>2011</b>
Cash and cash equivalents	588,553	582,067
Investments, at market value	1,103,303	1,205,128
Grants receivable	15,000	15,000
Accounts receivable	3,550	10,500
Prepaid expenses	8,027	8,289
Property, at cost		
Furniture and equipment	113,309	112,607
Less: Accumulated depreciation	(100,818)	(93,530)
Total:	12,491	19,077
Deposits	5,441	5,441
<b>Total Assets</b>	<b>1,736,365</b>	<b>1,845,502</b>
<b>Liabilities and Net Assets</b>		
Accounts payable	26,104	28,085
Accrued vacation	23,399	21,610
<b>Total Liabilities</b>	<b>49,503</b>	<b>49,695</b>
Net assets:		
Unrestricted net assets	1,261,315	1,342,809
Board designated fund	129,004	101,174
Temporarily restricted net assets	296,543	351,824
<b>Total Net Assets</b>	<b>1,686,862</b>	<b>1,795,807</b>
<b>Total Liabilities and Net Assets</b>	<b>1,736,365</b>	<b>1,845,502</b>



# STATEMENT OF ACTIVITIES

## YEAR ENDED JUNE 30, 2012

### Changes in unrestricted net assets

<b>Revenue and Support</b>	<b>2012</b>	<b>2011</b>
Corporate and foundation grants	479,311	331,845
Contributions	523,415	475,916
Interest income	13,187	13,545
Program revenue	18,222	21,786
Realized & Unrealized Loss / Gain on investment	(97)	13,461
Total unrestricted revenue	1,034,038	856,553
Net assets released from restrictions		
Satisfaction of program restrictions	149,679	353,237
Total unrestricted revenue and other support	1,183,717	1,209,790
<b>Expenses</b>		
Salaries	541,898	549,107
Employee benefits	43,193	40,094
Payroll taxes	43,589	45,250
Office and administration	82,884	65,969
Medical research	37,200	29,520
Physician Education	57,135	50,844
Patient Education	56,838	62,373
Legal and accounting	56,824	57,149
Rent	57,067	61,502
Medical conferences presented	123,248	107,821
Travel	21,264	28,742
Postage	40,769	45,761
Printing	39,817	50,860
Outreach	28,367	22,829
Depreciation	7,288	9,730
Total expenses	1,237,381	1,227,551
Decrease in unrestricted net assets	(53,664)	(17,761)
Changes in temporarily restricted net assets		
Corporate and foundation grants	94,398	239,300
Net assets released from restrictions	(149,679)	(353,237)
Increase in temporarily restricted net assets	(55,281)	(113,937)
Total increase in net assets	(108,945)	(131,698)
Net assets, beginning of year	(131,698)	-
Net assets, end of year	(240,643)	(131,698)

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## CORPORATE PARTNERS

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The Corporate Partnership Program provides a way for the Spondylitis Association's pharmaceutical partners to positively impact the lives of those affected by spondylitis by contributing to the organization's general operating budget. SAA also receives additional corporate support for special programs.

### PLATINUM PARTNER 2012



### ADDITIONAL CORPORATE SUPPORT FOR 2012



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## FOUNDATIONS

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SAA's Foundation funders make a positive difference in the lives of the spondylitis community by supporting SAA's general operating budget as well as funding special projects. SAA would like to recognize and thank the following foundations for their generosity and support.

Blank Charitable Foundation  
Cecile & Fred Bartman Foundation  
Community Foundation Alliance  
Ellen & Marshall Cole Philanthropic Fund  
Fred & Mabel R. Parks Foundation  
Kautz Family Foundation  
Koven Foundation  
Jean & E. Floyd Kvamme Foundation

Murdy Foundation  
The Roger Klauber Family Foundation, Inc  
Simon Family Foundation  
Stupp Bros. Bridge & Iron Co. Foundation  
Sydney T. Levenson, M.D. Foundation  
Thistle & Rose Foundation  
Young Foundation

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## GIFTS IN KIND

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The Spondylitis Association would like to thank the following supporters who have donated in-kind goods and service between July 1, 2011 and June 30, 2012.

Dennis Bolton Enterprises  
Craig Gimbel, DDS  
Alan Hirsh  
Leslie Kautz  
Quexion, LLC

Michael Rakosi  
Jay Ross at GR8PCDR  
Michael Smith  
Joel Stratte-McClure  
Sundance Press



# LEADERSHIP CIRCLE

The Leadership Circle is a distinguished group of dedicated individuals who made gifts of \$1,000 or more between July 1, 2011 and June 30, 2012. Through their participation, Leadership Circle member contributions support all SAA programs. Their generosity demonstrates the strength of their commitment to the mission of SAA and underscores the important role that Leadership Circle members play in helping to sustain the organization today and in the future.

## \$50,000

Stephen & Grace Becker  
Jean & E. Floyd Kvamme Foundation

## \$25,000

John Eckermann  
Kautz Family Foundation

## \$10,000 to \$20,000

Cecile & Fred Bartman Foundation  
Fred & Mabel R. Parks Foundation  
Herb & Barbara Shear  
Diane Williams

## \$5,000 to \$9,999

Elizabeth & Daniel Davis  
Deidra & Niki Krutop  
Nancy Regan  
Laurie M. Savage

## \$2500 - \$5000

Community Foundation Alliance  
Charlotte Howard  
Wallace Hwang  
Margo & Stanley Itskowitch  
Leslie Kautz  
James Kelly  
Brian MacKenzie

Brian Mason  
Karen & Chris McCallion  
Doug Mortimer  
Murdy Foundation  
Paula Olsiewski, Ph.D.  
Michael Pianin  
John Reveille, M.D.  
Thistle & Rose Foundation  
Jennifer Visscher

## \$1000 - \$2499

Keith & Celia Arnaud  
Buck & Leslie Balkind  
Brian Berman  
Blank Charitable Foundation  
Bradley & Marla Bockhorst  
Harry & Jane Bruckel  
Web Carr  
Diane Crystal  
Mr. Chris Deininger  
John Duvall  
Judy Fiskin  
Britt-Louise Fletcher  
Andrew & Lauren Forbes  
Alan J. Fraser  
Susan Gallagher  
Jason Ganetsky

Fabio & Wei Garofolo  
Craig Gimbel, D.D.S.  
Bill Giser  
Alan Glaser  
Eric Goldstein  
Philip Gully, III  
Scott Haber  
David Hallegua, M.D.  
Laura Hamilton  
Elmer & Arlene Hansen  
Amanda Harrell  
Dr. Robert & Barbara Hasty  
Todd & Kathleen Herzog  
Susan & Stephen James  
Bradley P. Johnson  
Jonathan Lathrop  
Brian R. Mann  
Marshall-Rismiller & Associates  
David Eric Moore  
Nancy & Dan Morgan  
Jane Morrill  
Christopher Noble  
Maria & Martin Nyvall  
Dr. Katharine O'Brien  
Michael Patterson  
Donald Petersen  
Ann Marie Prazak

Timothy Quinn  
Chris Rabe  
Luther Ragin, Jr  
Gerald Rosenfeld  
Cathy Rutter  
Dennis & Beverly Sansom  
Randall Sapadin  
Laurie Saylak  
Laura G. Schafer  
Ronald Schanze  
Jeffrey & Diana Schmitt  
Karrie Shogren, Ph.D.  
Melanie Smith  
Clarence So  
Traude Steidlmayer  
Stupp Bros. Bridge & Iron Co.  
Foundation  
Roger Tachuk  
Barry & Christine Tobias  
Alison Toth, M.D.  
Robert W. Ulrich, Pharm.D.  
Barbara Van Alstine  
Wear Your Music Charity Program  
Tom & Barbie West  
Joe Wickwire  
Hilary Wilson

# QUEST LEGACY SOCIETY

The *Quest Legacy Society* recognizes those individuals who have taken the special step to include SAA in their estate plans through charitable bequests, trusts, insurance, or other forms of deferred giving. Among the organization's most valued supporters, members of the *Quest Legacy Society* have decided to continue the fight against spondylitis beyond their own lifetimes, bestowing upon all those affected by the disease, their families, and future generations a reason for hope. Information about the *Quest Legacy Society* can be found on SAA's website at:

[www.spondylitis.org/quest](http://www.spondylitis.org/quest)

## *SAA is honored to recognize these Quest Legacy Society members:*

Stephen and Grace Becker  
Jane & Harry Bruckel  
Cecelia Bunch  
Means Davis, Jr.  
Richard and Deanna Day  
Harvey R. Derscheid  
Alan Fraser

David Fulle  
Craig B. Gimbel Family Trust  
Robert and Barbara Hasty  
David S. Hallegua, MD  
Karin & Richard Howard  
Charlotte Howard  
Leslie B. Kautz

Jennifer Layden  
Linda Lovello  
Brian MacKenzie  
Jane & Hugh McGonagle  
Charles Mol  
Nancy Regan  
Zoanne Sager and the late

Stephan Howard Kramer  
Randall Sapadin, The Maria  
Coppola Foundation  
Laurie M. Savage  
Katherine Sprouse  
Hilary Wilson  
Darren B. Wolpert



## *Remembered in perpetuity (year donation received):*

Lillian Buckley (2001)  
Raymond & Mary Jean Cassidy (2004)  
Gregory Fallowfield (2004)  
Marvin Kallison (2009)  
Nicholas Karatsoulis (2002)  
Barbara Murchison (2008)  
Nicholas Pregibon (2013)  
Shirley Symington (2007)  
Ira Thompson (2002)

# MEMBERSHIP & INDIVIDUAL DONORS

Over sixty-eight percent of the Spondylitis Association's operating revenue in fiscal year 2012 came from individuals and family foundations.

Every effort has been made to ensure that this list is accurate and complete, but in the event of an error or omission, we extend our apologies and encourage you to contact Diann Peterson, Director of Annual Giving at 800-777-8189, ext. 226 or by email at [diann.peterson@spondylitis.org](mailto:diann.peterson@spondylitis.org) so that proper recognition may be ensured in the future.

Also note that many donations given through workplace campaigns such as the Combined Federal Campaign and United Way are received anonymously. If you have given through one of these campaigns, please let us know so that we may acknowledge your generosity and ensure that you continue to receive your member benefits.

## \$500 to \$999

Caroline & Rob Abrom  
Charles Adams, Jr.  
Vasser Bailey  
Robert & Christine Baldoni  
John Barnes, M.D.  
Michael Barton  
Gerald & Estelle Becker  
Todd Bruckel  
William & Lauraine Buehler  
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Ruben Burgos-Vargas, M.D.  
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Jerry Lim  
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Heather Lopane  
Anna & Chris Lynch  
Florence Magassy  
Susan M. Mandell  
Marvella McEly  
Ann E. McLarty  
Molly McLaughlin  
Sandra L. Oakes  
Betty Opbroek  
Bryan Peeler  
Mike Perzanowski  
Diann Peterson  
Ivo Ray Peterson  
Katherine Poppe  
Len Poteshman  
Michael Rakosi  
Dan L. Robinson

Steve Roethe  
David Rose  
Michael Rothermund  
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Joseph Scrocco  
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Justin & Rachel Shifrin  
Kevin Spillane  
Maria Stafford  
Pattie Stewart  
Markos I. Tambakeras  
Robert & Donna Teresi  
John & Mary Jo Thayer  
Brian & Jill Tichenor  
Jayne & Kelly Tien  
Fadlo & Justine Touma  
David Towery  
John Trotter  
David & Christine Vernier  
Dirk Visser  
Robert W. Warren, M.D.  
Tom Wilkinson  
Janet & David Williams  
Darren B. Wolpert  
Mary Ann Wray  
Steve & Mimi Young  
Young Foundation

## \$250 to \$499

Emily Amico  
Jake Aronov  
Betty & George Baffa  
Betsy Baker

Andrea Barnett  
James Barnett  
Jennelle Barton  
Angela Bartzen  
Barbara Anne Bittner-Killeen  
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Robert Hecox  
Joseph & Patricia Herbers  
Frank Hershkowitz





*"One thing that I really appreciate is that SAA follows up our annual donation with a phone call to thank us and to ask if there's anything else that you can be doing. I don't know of any other charity who calls their donors in this way (many others call to ask for more donations, but not to offer help and thanks). You are doing a great job, and I hope you know how appreciative the AS community is of your efforts!"*

*~ Jennifer*

Kenneth & Linda Honer  
Cheryl Hopper  
Shirley Hubers-Boundy  
David & Katharine Hutchison  
Katherine Ielmini  
Ralph Izard  
Jerry Jensen  
Therese Jervey  
Danyle Johansson  
Sheldon Kapitza  
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Barry & Amy Misbin  
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Mary Vieth  
Karenn Wahl Colby  
John Walz  
Anna West  
Tiffany Westrich  
Tim White  
Don Wiedemann  
Lauren Wiener  
Maria Wilcox  
Scott D. Wood

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Harry & Trudy Angel  
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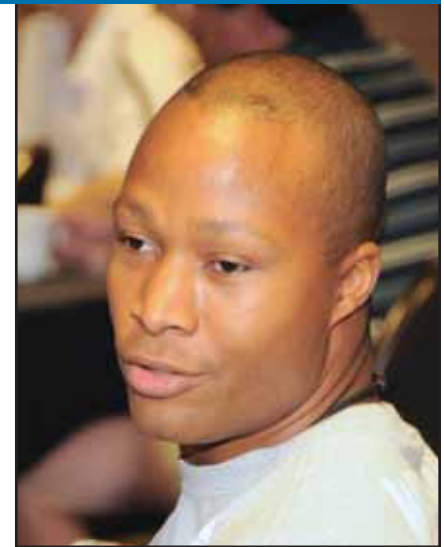
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*"This organization has given me so much information and I am so thankful for it. Since being diagnosed I've been doing a lot of reading and never knew that people could possibly be so caring. Information is the key to living with these conditions and I appreciate it so much. I cannot thank you enough!!! Many blessings and thanks." ~ Sandi*



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