

MOVING **FORWARD**

2014 Annual Report



formerly known as the RLS Foundation

Restless Legs Syndrome Foundation, Inc., (dba) Willis-Ekbom Disease Foundation, is dedicated to improving the lives of the men, women, and children who live with this often devastating disorder. The organization's goals are to increase awareness, to improve treatments, and through research, to find a cure for WED/RLS.

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The Willis-Ekbom Disease Foundation Board of Directors held meetings on:

November 1-3, 2013
Denver, CO

February 25, 2014
Webinar Meeting

May 5, 2014
Webinar Meeting

June 20-22, 2014
St. Louis, MO

July 7, 2014
Conference Call

August 26, 2014
Conference Call

MOVING FORWARD

*"If everyone is moving forward together,
then success takes care of itself."*

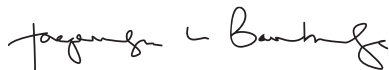
– Henry Ford

As we begin the new year, I am excited about the progress made by the Willis-Ekbom Foundation in 2014. Our dedicated staff, members of the board of directors, medical and scientific advisory board, and volunteers worked together to raise awareness and educate the public about WED/RLS. The expansion of the Quality Care Center initiative is helping individuals all around the world find the support and treatments they need to enjoy productive lives. Our free online webinars brought expert physicians into the homes of hundreds of participants on cutting edge topics. Our website continues to experience growth as it serves to educate the WED/RLS community. In addition, our presence on the major social media platforms continues to grow as a resource and support system for those who suffer from WED/RLS. I thank all of our members, volunteers, and staff who make these efforts possible.

The Foundation continues its commitment to research through our grant program. With the generous research donations received, we were able to fund a research grant that is designed to help develop new treatment options leading to better symptom control. With your support, the dedicated members of the Scientific Advisory Board are committed to funding research to improve the quality of life of WED/RLS patients.

Thank you for being part of a successful 2014 and we look forward to much success in 2015. We could not do it without your help and support. Together we strive to work towards increased awareness, improved treatments, and a cure for Willis-Ekbom Disease in the near future.

Sincerely,



Jacquelyn (Jacci) Bainbridge, PharmD
WED Foundation Board Chair 2014



**Jacquelyn (Jacci)
Bainbridge, PharmD**
*Chair, Willis-Ekbom Disease
Foundation Board of Directors*

Scientists Link BTBD9 Gene with WED/RLS Foundation-funded study sets stage for further research

Scientists at Emory University have made important progress toward understanding the role of genetics in WED/RLS. In a recent study funded in part by the WED Foundation, a research team led by Subhabrata Sanyal, PhD, found the gene known as BTBD9 contributed to WED/RLS symptoms in the fly *Drosophila*. Researchers also observed the gene's effect on iron metabolism and the function of the dopaminergic system in *Drosophila*.

BTBD9 is among several genes that have been linked with WED/RLS in past research. In the recent study, scientists removed BTBD9 from flies and observed a subsequent increase in WED/RLS symptoms: motor restlessness and disturbed sleep. These symptoms improved when the flies were given pramipexole (a dopamine agonist commonly used for treating WED/RLS in humans). Using human tissue culture cells, scientists also observed an effect of BTBD9 on iron mobilization pathways in the brain.

“Funding from the WED Foundation was crucial in our efforts to generate a genetic model of WED/RLS in flies.”

“The major significance of our study is to highlight the fact that there might be a genetic basis for WED/RLS,” says Dr. Sanyal. “Understanding the function of these genes also helps to understand and diagnose the disease and may offer more focused therapeutic options that are currently limited to very general approaches.”

Drosophila, commonly known as a “fruit fly,” is used as a genetic research model for a number of diseases because certain genes in *Drosophila* (such as BTBD9) closely match those of humans. Also, techniques to remove genes for genetic analysis are well developed and rapid in the fly.

The new research findings set the stage for further exploration of the role of BTBD9 in WED/RLS, as well as for using *Drosophila* as an animal model. “Once it becomes clear how exactly BTBD9 alters the functioning of dopaminergic neurons (these studies are currently underway in my

laboratory at Biogen Idec), it might be possible to intervene pharmacologically and develop targeted WED/RLS treatments,” says Dr. Sanyal.

Support from the WED Foundation was crucial to the recent research, says Dr. Sanyal. “It is important to note that our work on WED/RLS has not been supported directly by the National Institutes of Health, and therefore, the entire work would not have been possible were it not for the support we received from the WED Foundation.” Grant funds were used to support a talented postdoctoral candidate, Dr. Amanda Freeman, who carried out most of the work, as well as to fund other essential activities.

The study has been highlighted in *Science Magazine* and published in three peer-reviewed journals (see below).

For an overview of research supported by the WED Foundation, please see the handout *WED Foundation Research Grant Program*, available from the Foundation at info@willis-ekbom.org or 507-287-6465, or by using the form on page 23.

Hurtley, Stella and Maria Cruz, eds. 2012. “Restless Flies, Fragmented Sleep.” *Science*, June 22, 1483.

Freeman AA, Syed S, Sanyal S. 2013. “Modeling the genetic basis for human sleep disorders in *Drosophila*.” *Commun Integr Biol* 6(1): e22733. doi:10.4161/cib.22733.

Freeman AA, Mandilaras K, Missirlis F, Sanyal S. 2013. “An emerging role for Cullin-3 mediated ubiquitination in sleep and circadian rhythm: insights from *Drosophila*.” *Fly* (Austin) 7(1): 39–43. doi:10.4161/fly.23506.

Freeman A, Pranski E, Miller RD, Radmard S, Bernhard D, Jinnah HA, Betarbet R, Rye DB, Sanyal S. 2012. “Sleep fragmentation and motor restlessness in a *Drosophila* model of Restless Legs Syndrome.” *Curr Biol* 22(12): 1142–48. doi:10.1016/j.cub.2012.04.027.

WED Foundation Certifies First International Quality Care Center

In March, the Foundation's Board of Directors certified the Innsbruck Medical University Sleep Lab and Sleep Disorders Outpatient Clinic as a WED/RLS Quality Care Center. Located in Austria, the Innsbruck clinic is the first international center in the Foundation's Quality Care Center program.

"The Innsbruck Quality Care Center demonstrates the commitment of healthcare providers on the international level to collaborate and share research and innovative treatment practices to provide the highest quality of care for those living with WED/RLS," says Jacqui Bainbridge, chair of the WED Foundation Board of Directors.

Birgit Högl, MD, is director of the Sleep Lab and Sleep Disorders Outpatient Clinic in Innsbruck. The Innsbruck clinic will "improve education and promote sharing of best practices, thereby improving health care for the patient community. This program seeks to improve the quality and accessibility of care for individuals with WED/RLS in the European community," says Dr. Högl.

The WED Foundation launched the WED/RLS Quality Care Center Program last year to improve diagnosis and treatment for people who have the disease.

WED/RLS Quality Care Centers are recognized as leaders in the field, serve as liaisons to primary care providers and support groups, and are listed in Foundation materials so that patients and providers can use their services. Certification is based on criteria developed by the WED Foundation Medical Advisory Board and requires a high level of expertise and experience treating WED/RLS patients.

Through education, sharing of best practices and quality improvement projects, the program aims to help the WED/RLS community overcome persistent barriers to effective diagnosis and treatment.

To learn more about the WED/RLS Quality Care Center Program, visit willis-ekbom.org/quality-care-program.



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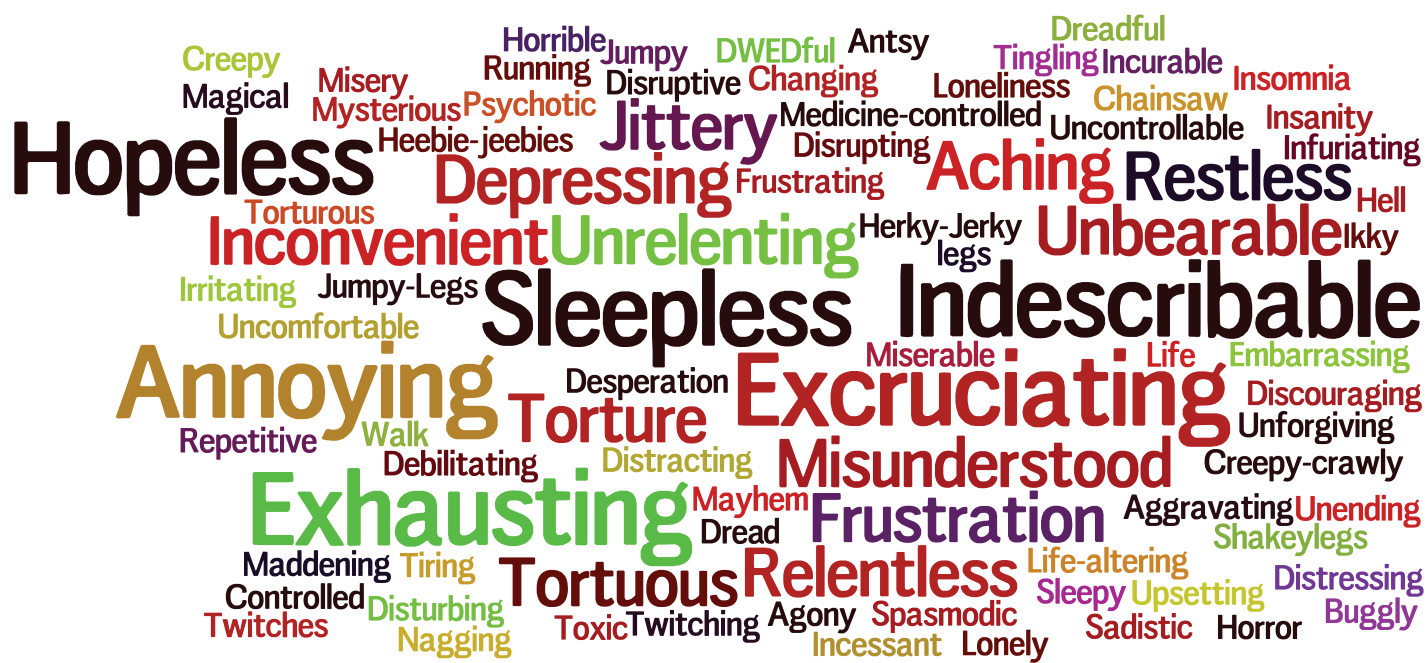
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In a word, WED/RLS is....



WED Foundation adds... HOPE

Words That Say “You Are Not Alone”

Recently the WED Foundation created a word cloud – a graphic created from a list of words. The Foundation asked people to describe in one word what living with WED/RLS was like, then used those words to make a word cloud.

This word cloud is amazing. It is informational. It is truthful. Most of all, it is scary and depressing. Terms such as *herky-jerky legs*, *buggly* and *ikky* can make this disease sound trivial and bearable, but these words also describe what WED/RLS feels like. *Misunderstood* is a fact of life most of us have lived with for a long time. Historically, we have not been taken seriously, and in many, many cases this is still true.

Even when we get brave enough to admit that WED/RLS is *insanity*, *unending* and *tortuous*; friends, family members and medical professionals do not take us seriously. In their minds, having restless legs, arms or other body parts is minor – a small annoyance at best. I remember when fibromyalgia and chronic fatigue syndrome were considered maladies made up by people who were simply lazy. Now they are accepted and widely known as real conditions; the public at large knows exactly what they are.

I was thinking about what words might be used to create word clouds for other chronic conditions or diseases. Probably most of the words in our word cloud (such as *relentless*, *excruciating*, *unrelenting* and *incurable*) can be used to describe other diseases. Take out those words, plus the ones such as *heebie-jeebies*, and you are left with two that are major players in our world.

The first is *chainsaw*. While this may get chuckles, it is a deadly serious word. Too many people have said they would like to cut off their legs just to get away from the misery but are afraid of phantom restlessness. Name one other disease where you would think about cutting off part of your body rather than enduring the feelings. We are not talking about pain here (although many suffer pain along with the restlessness); pain is accepted in our society – having jumpy legs or arms is not.

The other word that makes this word cloud unique is *lonely*. I fully understand that every person at one time or another feels lonely. But this is a loneliness that comes when you are surrounded by people who have no clue what you are going

through. Chemo patients, dialysis patients, people with dementia – all have enormous support networks, which is wonderful. WED/RLS affects from 7 to 10 percent of the population, and yet we walk the floors at night with no one beside us. We look out at the darkness without having anyone holding our hands.

This word cloud can be depressing – just like our lives can be when we are dealing with WED/RLS. But I prefer to look at it as something new and refreshing that can be used to create awareness, open conversations and best of all, remind us that we are not alone. I may not have the exact same symptoms as you, take the same medications or have the same outlook – but I know what you are going through.

The same moon shines over us all. So while we may not know each other personally, we can work together so that one night, if we find ourselves walking the floors, WED/RLS will not be the reason.



Kathy Page
2014 Development Committee Chair

WED Foundation Levels of Giving

At the WED Foundation, we rely on private donations to make our work possible. While we do receive some industry grants, our lifeblood is you and your commitment to the mission. We cannot thank you enough for the support you give every year.

Unrestricted Gifts give the Foundation the flexibility to target funds for programs and projects that are in the most need of financial support.

Restricted Gifts may be designated to two areas: education and research. Donations to these funds are earmarked for special projects that may complement your intentions more closely.

Monthly Giving allows you to spread your donation out over the year and enables us to count on a more constant stream of gifts. You can also choose to restrict your gifts with this option. Monthly giving can be done by setting up a recurring credit card gift or an automatic bill pay/donation each month with your bank.

Assets to Give are the quickest and easiest way to give to the WED Foundation. Checks payable to the WED Foundation or credit card donations completed online are fully deductible and provide an immediate source of income for programs.

Appreciated Securities are gifts that allow you to eliminate the burden of capital gains taxes. In nearly all cases, you are able to claim a charitable income tax deduction equal to the fair-market value of the securities.

Bequests given through your estate at the time of your death are an attractive way to make sure that your interests are preserved. When you let us know about your plans to give a gift in your estate, you become a member of our Ekbom Heritage Society, an elite group at the Foundation committed to our mission and vision for the future.

If you would like to learn more about planned giving, please request our *Giving Avenues* brochure or contact us at 507-287-6465 or info@willis-ekbom.org.

Levels

We value all of our supporters at every level. Each of you makes an important impact on the programs that help so many living with restless legs syndrome (Willis-Ekbom disease). *Thank you!*

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 Harriet P. Grimes
 Mr. Timothy Guirl
 Wanda Rene' Guyton
 Mr. Ron Haedt
 Mrs. Claire Hakim
 Mrs. Elizabeth M. Haning
 Donald T. Hansen
 Mr. and Mrs. Craig Hanson
 Evelyn Harper
 Mr. Roland W. Hart
 Mr. Thomas Hartzog
 Bettye J. Hauser
 Mrs. Betty Headley
 James Heinz
 Mr. George Henry
 Mary K. Hepburn
 Renee Hermanson
 Lynne Herndon
 P. L. Herron
 Ms. Michelle C. Hester
 Dr. Susan Hetherington
 Barbara Hirschy
 Mrs. Delpha A. Hirth
 Ms. Connie Hodge
 Mrs. Nancy Holtkamp
 Mr. Ron R. Hopperton
 Mrs. Irma Hornbeck
 Mr. and Mrs. James Horton
 Jerry & Shirley Hosek
 John T. Hubbard Jr.
 Ms. Paula Hughes
 Mary L. Hunt
 Mrs. Sharon Huntington
 Thomas & Vicki Hurwitz
 Betty L. Hutchins
 Jean H. Hutchins
 Lucille L. Hynes
 Ms. Kathleen Jefferis
 Jean D. Jensen
 Mr. Jim Jessup
 Byron C. Jones PhD
 Ms. Priscilla Joseph
 Mr. Helmut Junge
 Norman Katz
 Mrs. Linda M. Kawtoski

Ms. Judith Kaye
 Mr. Donnie Kee
 Mr. Wiley C. Keel
 Mary C. Kehlhem
 Sarah P. Kellen
 Mr. Michael J. Keogh
 Mr. Robert Kern
 Dr. Michael Kikta
 Mr. Calvin Kimmel
 Ms. Nancy M. Kindness
 Mr. Mike Kirby
 Prof. Donald C. Kleinfelter
 Mr. Cliff T. Kleintop
 Jean & Ed Knapp
 Lt. Col. (Ret) Paul B. Knutson
 Cletus Koehler
 Ms. Helen Koehn
 Rosemary Kosmak
 Mrs. Kathleen Kotchi
 Diane Kuehn
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 Mr. Michael Kun
 Faye G Kunze
 Mrs. Judy Kyle
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 Ms. Anne Lampe
 Mr. Michael Lanasa
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 Ginger Miller
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 Scott Levad
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 Mrs. Sherry C. Licari
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 Mrs. Saida S. Malarney
 Mr. William Maloney
 Mr. Frank Manchester
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 Ms. Christina Marciniak
 Carol Mayer Marshall
 Mr. Leonard Marshall
 Ms. Susan Marshall
 Mr. David Martens
 Mrs. Baldwin Martin, Jr.
 Paul S. Mattheiss
 Alice J. and Thomas M. Maxin
 Mr. John May
 Cathy A. McCarthy
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 Park McGinty
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 Mr. Howard McNally
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 Medtronic
 Elsa Michitsch
 Mr. Andreas Mihos
 Mrs. Bonnie Miller
 Ms. Dorie Miller
 Ms. Denise Millman
 Sally Mills
 Mrs. Ida R. Minor

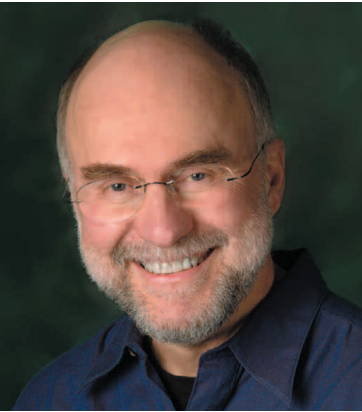
Mr. Darius Mistry
 Mr. George Mitchell
 Ms. Nisha Mohammed
 Judy C. Monostory
 Mr. Robert Montcalm
 Dr. William L. Montgomery
 Mrs. Doria Moodie
 Mr. Jonathan T. Moore
 Dr. Robert A. Moran
 Mr. Marc Morgenstern
 Steve Morton
 Mr. Charles Moyer
 Mrs. Diane P. Moyer
 Ms. Freya Mueller
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 Dr. Alan Newman
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 Jeanine Nix PhD LCSW
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 Mr. Gerald Norris
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 Ms. Linda Orcutt
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 Doris B. Stretch
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 Tyco Employee Matching Gift
 Program
 Mr. T Michael Ulwelling
 United Way of Bergan County
 United Way of Tri-County
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 Mrs Albert E. Willms
 Ms. Jean Wimer
 Ms. Lynsey Winner
 The Honorable Thomas Witzel
 Mr. Eduard Wojczynski
 Lucy H. Wong
 Mrs. Linda R. Wood
 Mr. Frederic Worden
 Mr. Cody Wray
 Ms. Marlene Zerbe
 Ms. Linda Zukiwski

Thank You!

Financial Report



Régis Langelier, PhD
*WED Foundation Board
Treasurer*

Thank you for your support and commitment to the Foundation in 2014! Individual donors continued to show strong support by contributing 77% of the Foundation's total revenue this year. The fiscal 2014 end of year match fundraiser was successful beyond our expectations. This underscores the importance of our donors contributions to supporting the mission of the Foundation.

The WED/RLS community continues a focus on this disease using social media, local and national volunteers and members. We educate the general public through online webinars, support group meetings and educational materials. Funding outstanding research grant proposals and promoting the certification of Quality Care Centers supports the mission of the Foundation to be a trusted source of non-biased information.

The Finance and Audit Committee continues to monitor the budget to ensure that revenue and expenditures are in balance and to review forecasts for the coming year, making certain money is wisely spent in programs that benefit the WED/RLS community.

Each gift, regardless of the size, allows the Foundation to continue our mutual goals of awareness, education, better treatments and research leading to a cure.

This is my final year as treasurer and board member. I have strived to improve our investment strategies and to obtain a better dollar return. It has been a real pleasure, and honor, to serve on the WED Foundation Board.

Cordially,

A handwritten signature in black ink that reads "Régis Langelier". The script is fluid and cursive, with the first letters of the first and last names being capitalized and prominent.

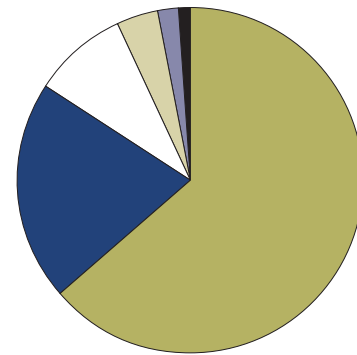
Régis Langelier, PhD
WED Foundation Board Treasurer

Willis-Ekbom Disease Foundation

Statements of Net Assets • September 30, 2014 and 2013

Assets	2014	2013
Cash and cash equivalents	\$ 184,424	\$ 284,498
Investments	445,951	316,761
Pledge receivable	10,000	0
Prepaid and accrued assets	20,810	18,837
Inventory	7,053	4,518
Fixed assets, net of depreciation	5,136	6,929
Total assets	\$ 673,374	\$ 631,543
Liabilities		
Accounts payable and accrued expenses	\$ 28,071	\$ 27,755
Research grants payable	17,500	0
Unearned revenue	16,748	35,280
Total liabilities	\$ 62,319	\$ 63,035
Net Assets		
Unrestricted	\$ 491,190	\$ 472,573
Temporarily restricted	119,865	95,935
Total net assets	611,055	568,508
Total liabilities and net assets	\$ 673,374	\$ 631,543

2014 Revenues

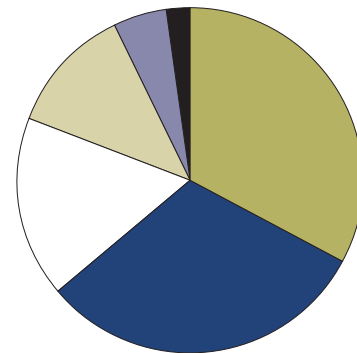


- Contributions 65% (unrestricted and restricted)
- Membership 21%
- Grants received 9%
- Investment income 3%
- Unrealized gain on investments 1%
- Miscellaneous income 1%

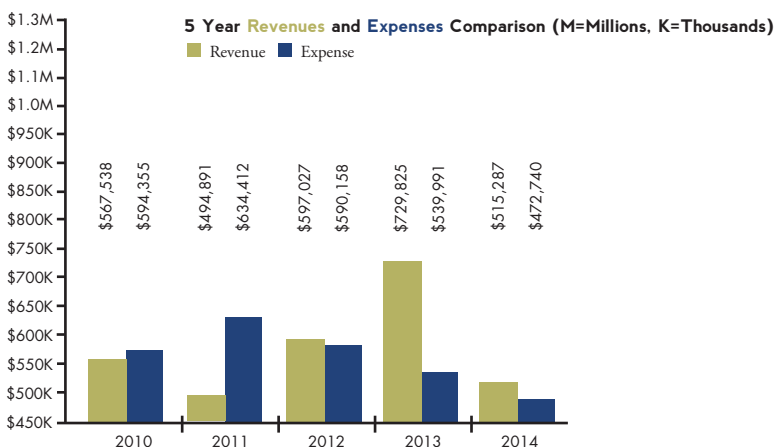
Statements of Activities • For years ending September 30, 2014 and 2013

Income	2014	2013
Contributions (unrestricted and restricted)	\$ 332,383	\$ 508,748
Membership	106,224	97,121
Grants received	48,532	96,120
Investment income	18,724	14,621
Miscellaneous income	331	4,615
Unrealized gain on investments	9,093	8,600
Total income	\$ 515,287	\$ 729,825
Expenses		
Programs		
Education and awareness	\$ 154,685	\$ 227,698
Membership	147,608	157,945
Research	54,472	20,860
Support Groups	10,743	17,095
Total program expenses	367,508	423,598
General and administrative	80,698	85,503
Fundraising	24,534	30,890
Total expenses	472,740	539,991
Net increase in net assets	\$ 42,547	\$ 189,834

2014 Expenses



- Education and awareness 33%
- Membership 31%
- General and administrative 17%
- Research 12%
- Fundraising 5%
- Support groups 2%





formerly known as the RLS Foundation

1530 Greenview Dr SW Suite 210
Rochester, MN 55902

Phone: 507-287-6465

Fax: 507-287-6312

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www.willis-ekbom.org

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FORWARD