



## 2016 Annual Report

**Because we don't know what's possible**



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## Letter from the President

Dear Friends,

It has been a very exciting and successful year for the Mowat-Wilson Syndrome Foundation! In keeping with our mission statement, we have accomplished some amazing projects---here is the short list---

- *Launched the Mowat-Wilson Syndrome Foundation Medical Patient Registry in partnership with Genetic Alliance to gather medical information for researchers.*
- *Hosted the Mowat-Wilson Syndrome Foundation Seattle Medical Forum with geneticists, Dr. Wilson and Dr. Adam, as well as other distinguished speakers.*
- *Donated \$5000 to the Kansas University Medical Center MWS stem cell research project headed by geneticist, Dr. Butler (total contribution by the MWSF of \$20,000 over 2 years).*
- *Re-designed and re-launched the MWSF website with incredible new graphics and appealing and useful content for MWS families, friends and supporters ([www.mowat-wilson.org](http://www.mowat-wilson.org)).*
- *Hosted MWSF Beach Day and Atlanta Pool Party events for the MWS families to socialize and support each other.*
- *Participated in Rare Disease Day events around the country to raise awareness about MWS.*
- *Fundraised enough monies to host our 2017 Mowat-Wilson Syndrome Foundation International Family Conference in June in Washington, D.C. We are expecting 200 attendees and their families for the 2-day event.*

The Board of Directors of the MWSF is engaged in supporting the MWS community in multiple ways. We ask that you will also support our mission and our projects by any or all the following ways---

- Sign up for our MWSF newsletter
- Join our social media sites
- Volunteer at a MWSF event
- Join a committee
- Make a donation

Please visit [www.mowat-wilson.org](http://www.mowat-wilson.org) for more information

All of these accomplishments and future projects have been made possible by an all-volunteer Board of Directors, Medical Advisory Board and our generous and caring supporters. Thank you!

*Susan Triunfo*

President

**The Mowat-Wilson Syndrome Foundation**





# Mission Statement

**The mission of The Mowat-Wilson Syndrome Foundation is to enhance the lives of people affected by Mowat-Wilson Syndrome by providing family support, raising awareness, and supporting research and education.**

## NORTHWEST REGIONAL MEDICAL FORUM

**October 15, 2016 - Seattle, WA - 49 Individual Participants in Attendance**

### NORTHWEST REGIONAL MEDICAL FORUM

October 15, 2016 • Seattle



The Medical Forum was organized by Dr. Margaret Adam of Seattle Children's Hospital for families and medical students interested in learning more about the syndrome. Doctors Meredith Wilson and Jay Vivian presented updates on scientific studies related to Mowat-Wilson Syndrome.

Workshop topics included:

- Seizure Management, Edward J. Novony, M.D.
- Bowel Management, Lusine Ambartsumyan, M.D.
- Augmentative Alternative Communication, Marci Ravelli, M.S. CCC.SLP

The Northeast Medical Forum was streamed live from Seattle on the Mowat-Wilson Syndrome Foundation Facebook page. All videos are available to watch and share with friends, families, doctors and therapists. Mowat-Wilson Syndrome families always enjoy meeting each other and sharing experiences!!



## NORTHEAST REGIONAL EVENT

**August 21, 2016 - 20 Families Participated  
Harkness Memorial Park - Waterford, CT**

The Mowat-Wilson Family Beach Day is an informal and relaxing day when families gather together to enjoy themselves and exchange experiences. This year 20 families attended the annual Beach Day celebration. Opportunities to gather are important for Mowat-Wilson Syndrome families. Amidst the fun activities, parents share experiences, goals, and hopes. Mowat-Wilson families depend on a strong community network.



## SOUTH REGIONAL FAMILY POOL PARTY & BBQ

**August 20, 2016 - Atlanta, GA - 6 Families Participated**

### SOUTH REGIONAL FAMILY POOL PARTY

August 20, 2016 • Atlanta



6 Mowat-Wilson families joined together for a fun filled day on August 20, 2016 in Tyrone, GA. The swimming pool with basketball hoop, putting green, corn hole, bocce ball and other games made for a great day of making friends. BBQ, hamburgers, hot dogs, & sides were served as Mowat-Wilson Syndrome kids of all ages welcomed the chance to mingle and learn from each other! MWS families will tell you that there is no better resource than each other. Everyone is looking for answers.

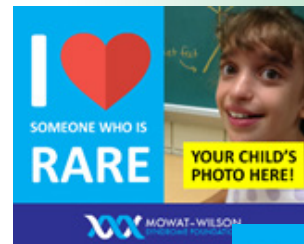




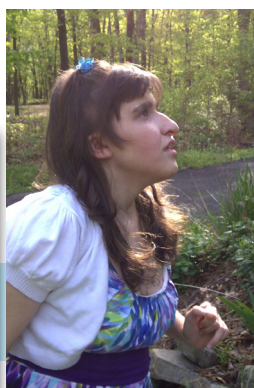
## NATIONAL RARE DISEASE DAY February 2016 - Participation Around the US

3 MWSF Board Members represented Mowat-Wilson Syndrome Foundation with presentation at local events in their state legislature offices and universities in February, 2016.

- Katie Fineberg, Connecticut
- Jessica Rakshys, New York
- Karen Baer, Texas



Social media cards provided by Foundation to over 40 families who wanted to share this message.



## FUNDRAISING CAN BE FUN AND CREATIVE *The Color Of Love: The Jillian Edition*

Jillian is beautiful and joyful 24 year old girl living in the Pocono Mountains region. A few years ago, Jillian was diagnosed with Mowat-Wilson Syndrome, a very rare genetic disorder that effects her physically and mentally. This book celebrates Jillian and her life by featuring designs that feature her doing some of her favorite activities. Also included in the book are 9 original designs donated by local artists. Help support Jillian and others living with this syndrome by purchasing a copy of The Jillian Edition Coloring Book. Proceeds raised will be donated to the Mowat-Wilson Syndrome Foundation.



## MOWAT-WILSON SYNDROME FOUNDATION GRANT RECIPIENT THROUGH Genetic Alliance

The Mowat-Wilson Syndrome Foundation is extremely pleased to announce that we are the recipient of a grant through Genetic Alliance to establish a MWS patient registry using their Platform for Engaging Everyone Responsibly (PEER) to build and house the MWS patient registry.

Dr. Margaret Adam, MD, who is a member of the Mowat-Wilson Syndrome Foundation Medical Advisory Board, will serve as the primary scientific advisor for the MWS patient registry. Dr. Adam is Professor of Pediatrics, Division of Genetic Medicine at the University of Washington in Seattle, WA. Here is what Dr. Adam had to say about the registry.



Margaret Adam, MD,  
FAAP, FACMG

"It is with great pleasure that I write this letter in support of the partnership between the Mowat-Wilson Syndrome (MWS) Foundation and the PEER platform. As a clinical geneticist, I have had the opportunity to both care for individuals with MWS and to participate in clinical research projects to help further our understanding of this condition. As is true for many rare genetic conditions, our ability to collect clinically relevant information that can help physicians provide excellent patient care is limited because each provider has only a small number of patients with the condition. Therefore, to further our knowledge of the breadth of the condition requires engagement of the involved community and a platform in which information can be securely and accurately entered and curated. This in turn will allow expert clinical researchers to extract important information and identify rare complications that will aid physicians who care for individuals with MWS. After reviewing the PEER platform, I feel that it is ideal for this endeavor. As a scientific advisor to the MWS Foundation, I look forward to working with them on implementing this platform and bringing it to the greater MWS community."



# 2016-2017 Officers & Board of Directors

## **President**

*Susan Triunfo*

## **Vice-President**

*Deborah Curry*

## **Secretary**

*Karen Baer*

## **Treasurer**

*Annette Arnold*

## **Directors**

*Dave Curry*

*Jessica Rakshys*

*Laura Chrysostomo*

*Sandie Flannery*

*Katie Fineberg*

*Al Triunfo*

*Chris Campisi*

## Medical Advisory Board

*The Medical Advisory Board of the Mowat-Wilson Syndrome Foundation is a group of physicians who are among the most respected and experienced in their fields. All are currently practicing physicians who can also be affiliated with an academic institutions. Members of the Medical Advisory Board are appointed by the Boards of Directors and act in an advisory capacity in medical matters related to Mowat-Wilson Syndrome.*

### **Meredith Wilson, MD**

Clinical Associate Professor  
CHW Department of Clinical Genetics  
The Children's Hospital at Westmead  
Hawkesbury Rd., & Hainsworth St.  
Westmead NSW

### **Belinda Dickie, MD, PhD**

Assistant in Surgery, Co-Director, Colorectal  
and Pelvic Malformation Center  
Pediatric Surgeon  
Assistant Professor, Harvard Medical School  
Boston, Massachusetts

### **Margaret Adam, MD, FAAP, FACMG**

Associate Professor of Pediatrics  
Division of Medical Genetics  
University of Washington School of Medicine

### **Merlin Butler, MD, PhD, FFACMG - Chair**

Professor of Psychiatry, Behavioral Sciences and Pediatrics  
ABMG Certified Clinical Geneticist and Clinical Cytogeneticist  
Departments of Psychiatry & Behavioral Sciences and Pediatrics  
Kansas University Medical Center  
Kansas City, KS

### **Jose M. Garza, MD, MS**

GI Care for Kids  
Medical Director, Neurogastroenterology and Motility  
Children's Healthcare of Atlanta  
Atlanta, Georgia

### **David Mowat, MBBS, MRCP, DRACOG, FRACP**

Senior Staff Specialist  
Clinical Geneticist  
Sydney Children's Hospital  
Sydney, Australia



# MOWAT-WILSON SYNDROME FOUNDATION

## Balance Sheet As of December 31, 2016

	Total	
	As of Dec 31, 2016	As of Dec 31, 2015 (PY)
<b>ASSETS</b>		
Current Assets		
Bank Accounts		
1000 TOTAL BUS CHK (6107)	11,502.92	8,275.64
1001 Cash Reserved	45,000.00	20,000.00
<b>Total 1000 TOTAL BUS CHK (6107)</b>	<b>\$ 56,502.92</b>	<b>\$ 28,275.64</b>
In-kind donation clearing	0.00	0.00
<b>Total Bank Accounts</b>	<b>\$ 56,502.92</b>	<b>\$ 28,275.64</b>
Other Current Assets		
1050 Awareness Product Inventory	0.00	1,646.14
<b>Total Other Current Assets</b>	<b>\$ 0.00</b>	<b>\$ 1,646.14</b>
<b>Total Current Assets</b>	<b>\$ 56,502.92</b>	<b>\$ 29,921.78</b>
<b>TOTAL ASSETS</b>	<b>\$ 56,502.92</b>	<b>\$ 29,921.78</b>
<b>LIABILITIES AND EQUITY</b>		
Liabilities		
Total Liabilities		
Equity		
Retained Earnings	29,921.78	10,893.21
Net Income	26,581.14	19,028.57
<b>Total Equity</b>	<b>\$ 56,502.92</b>	<b>\$ 29,921.78</b>
<b>TOTAL LIABILITIES AND EQUITY</b>	<b>\$ 56,502.92</b>	<b>\$ 29,921.78</b>

## Profit And Loss January - December 2016

	Total	
	Jan - Dec 2016	Jan - Dec 2015 (PY)
<b>INCOME</b>		
4000 Non Profit Income	387.32	1,338.10
4001 Corporate Donations	3,198.38	6,238.21
4002 Individual Donations	37,209.76	23,148.94
4400 2016 Seattle Medical Forum Registration	4,200.00	
Non-Profit Income		722.95
<b>Total 4000 Non Profit Income</b>	<b>\$ 44,995.46</b>	<b>\$ 31,448.20</b>
4100 Sales-Promotional/awareness products	589.95	177.60
In-kind donation	424.11	367.78
Sales of Product Income		30.81
Sales-Promotional/awareness products (t-shirts, pens, lapel pins, rubber bracelets)	230.40	
<b>Total Income</b>	<b>\$ 46,239.92</b>	<b>\$ 32,024.39</b>
<b>COST OF GOODS SOLD</b>		
4101 Cost of Goods Sold	275.20	44.00
Supplies & Materials - COGS		320.28
<b>Total Cost of Goods Sold</b>	<b>\$ 275.20</b>	<b>\$ 364.28</b>
<b>GROSS PROFIT</b>	<b>\$ 45,964.72</b>	<b>\$ 31,660.11</b>
<b>EXPENSES</b>		
2030 Sales Tax on Promo products		6.84
5001 2016 Seattle Medical Forum	8,343.62	
6000 Bank Charges	311.92	123.86
7010 Office Expenses	65.95	
7020 Office/General Administrative Expenses	1,555.40	1,025.90
7030 Promotional	2,366.23	
Fundraising Expense	147.36	595.00
<b>Total 7030 Promotional</b>	<b>\$ 2,513.59</b>	<b>\$ 595.00</b>
7050 Research funding	5,000.00	10,000.00
8000 Insurance		744.00
8010 Insurance - Liability	794.00	
Dues & Subscriptions	75.00	
Labor or services donated	624.10	
Taxes & Licenses	75.00	135.94
<b>Total Expenses</b>	<b>\$ 19,358.58</b>	<b>\$ 12,631.54</b>
<b>NET OPERATING INCOME</b>	<b>\$ 26,606.14</b>	<b>\$ 19,028.57</b>
<b>OTHER EXPENSES</b>		
Miscellaneous	25.00	
<b>Total Other Expenses</b>	<b>\$ 25.00</b>	<b>\$ 0.00</b>
<b>NET OTHER INCOME</b>	<b>-\$ 25.00</b>	<b>\$ 0.00</b>
<b>NET INCOME</b>	<b>\$ 26,581.14</b>	<b>\$ 19,028.57</b>

In 2016 the Foundation allowed cash balances to build in preparation for the 2017 Family Conference in Washington, DC: June 29 - July 3, 2017

# MOWAT-WILSON SYNDROME FOUNDATION

## 2017 BUDGET (with 2016 comparison)

	2017	2016
<b>INCOME</b>		
Corporate Donations	\$ 3,358.30	\$ 3,198.38
Individual Donations	\$ 44,332.25	\$ 36,221.19
2016 Medical Forum Conference Fees		\$ 6,000.00
2017 Family Conference Fees	\$ 81,750.00	
2017 Family Conference Sponsorships	\$ 15,000.00	
Sales net of COGS		\$ 545.15
<b>TOTAL NONPROFIT INCOME</b>	<b>\$ 144,440.55</b>	<b>\$ 45,964.72</b>
<b>EXPENSES</b>		
2016 Medical Forum Expenses		\$ 8,343.62
2017 Family Conference Expenses	\$ 136,500.00	
Bank Fees	\$ 327.52	\$ 311.92
Office Expenses	\$ 69.25	\$ 65.95
Office G&A Expenses	\$ 1,633.17	\$ 1,555.40
Promotion	\$ 1,000.00	\$ 2,366.23
Fundraising Expense	\$ 500.00	\$ 147.36
Research Funding	\$ 1,500.00	\$ 5,000.00
Liability Insurance	\$ 833.70	\$ 794.00
Dues & Subscriptions	\$ 100.00	\$ 75.00
Labor/Services Donated	\$ -	\$ 624.10
Taxes & Licenses	\$ 75.00	\$ 75.00
Miscellaneous		\$ 25.00
<b>TOTAL NONPROFIT EXPENSES</b>	<b>\$ 142,538.64</b>	<b>\$ 19,383.58</b>
<b>NET INCOME</b>	<b>\$ 1,901.91</b>	<b>\$ 26,581.14</b>



## 2017 INTERNATIONAL FAMILY CONFERENCE

**June 29 - July 1, 2017 - Washington D.C**  
**Over 40 Families Already Registered**

Join us for two days filled with lectures, workshops, Q&A sessions and activities for parents, individuals with Mowat-Wilson Syndrome and siblings. Guest speakers include Dr. David Mowat and Dr. Margaret Wilson among many other specialists that will speak on topics that affect most families like: Bowel Management, Mobility, Adaptive Technologies, Advocacy, Grieving and Stages of Acceptance, Epilepsy, etc. It will be a great opportunity to meet other families and exchange experiences!

**CONFERENCE REGISTRATION – Save by March 31, 2017!**

Early registration discounted fees available until March 31, 2017.

Registration closes on May 31 or when venue maximum capacity is reached. Registration can be completed online or by mail. If you have any questions, please contact us at [conference@mowat-wilson.org](mailto:conference@mowat-wilson.org)

### LOCATION / HOTEL

The conference will be held at the Crystal Gateway Marriott Hotel in Arlington, VA. Rooms have been blocked for the families at a discounted rate of \$149/night.

### REGISTRATION FEES REFUND POLICY

Full registration fees will be refunded by 3/31/2017. 50% registration fees refunded by 5/31/2017. No refunds after 6/1/2017.

