

# **2016 Annual Report**

# Because we don't know what's possible





### 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).
- 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 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



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*



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











#### 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, MRCGP, 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) ASSETS Current Assets 1000 TOTAL BUS CHK (6107) 11,502.92 8,275.64 1001 Cash Reserved 45.000.00 20.000.00 Total 1000 TOTAL BUS CHK (6107) 56,502.92 \$ 28,275.64 In-kind donation clearing 0.00 0.00 \$ 56,502.92 \$ **Total Bank Accounts** 28,275.64 1050 Awareness Product Inventory 0.00 1,646.14 \$ **Total Other Current Assets** 0.00 \$ 1.646.14 **Total Current Assets** \$ 56,502.92 \$ 29,921.78 TOTAL ASSETS \$ 56.502.92 \$ 29.921.78 LIABILITIES AND EQUITY Liabilities Total Liabilities Equity 29.921.78 10.893.21 Retained Earnings 19,028.57 Net Income 26,581.14 **Total Equity** 56,502.92 \$ 29,921.78 TOTAL LIABILITIES AND EQUITY 56,502.92 \$ 29,921.78

#### Profit And Loss January - December 2016

Monter			Tot	tal	
400 Non Profit Income         387.32         1,308.00         6.00.20.20         2,308.00         6.00.20.20         2,308.00         6.00.20.20         2,308.00         6.00.20.20         2,308.00         2,308.00         2,308.00         2,308.00         2,308.00         2,308.00         2,308.00         2,308.00         2,308.00         2,308.00         2,309.00         2,309.00         3,308.00         3,309.00         3,308.00         3,309.00         3,			Jan - Dec 2016	J	an - Dec 2015 (PY)
4001 Corporate Donations         3,198.8         6,28.281           4002 Cindividual Donations         32,00.8         23,148,04           44002 Cindividual Donations         4,200.00         1           44002 Cindividual Forum Registration         2,200.00         722,05           Total 4000 Non Profit Income         \$ 44,995.6         \$ 13,448,00           4100 Sales Promotional/awareness products         589.5         177,00           Inkind donation         424.1         3,00.00           Sales Promotional/awareness products (t-shirts, pens, lapel pins, rubber bracelets)         200.00         200.00           Total Income         \$ 46,239.2         \$ 32,024.30           COST OF GOODS SOLD         275.20         \$ 32,024.30           Value of Goods Sold         275.20         \$ 32,022.30           Total Coc of Goods Sold         \$ 275.20         \$ 34,800.00           Sopplies & Materials - COOS         \$ 45,964.7         \$ 30,800.10           EXPENSES         \$ 45,964.7         \$ 31,600.11           EXPENSES         \$ 45,964.7         \$ 12,802.00           2003 Sales Taxo n Promo products         \$ 3,45.2         \$ 12,802.00           5001 2016 Seattle Medical Forum         \$ 3,45.9         \$ 12,802.00           7010 Office Expenses         \$	INCOME				
4002 Individual Donations         37,20,76         23,184,84           44002 216 Seattle Medical Forum Registration Non-Profit Income         722,35         722,35           Total 4000 Non Profit Income         \$ 44,954,68         \$ 13,466,20           14000 Sales-Promotional/awareness products         \$ 89,99         177,60           1 Nickind donation         \$ 20,30         30,00           Sales of Product Income         \$ 20,30         30,00           Sales of Product Income         \$ 20,30         \$ 30,00           Sales of Product Income         \$ 275,20         \$ 44,00           Sales of Product Income         \$ 275,20         \$ 30,00           Sales of Product Income         \$ 28,00         \$ 31,60           Sales of Product Income         \$ 28,00         \$ 31,60           Sales of Sales         \$ 28,00         \$ 28,00	4000 Non Profit Income		387.32		1,338.10
A400 2016 Seattle Medical Forum Registration   72.295   72.200	4001 Corporate Donations		3,198.38		6,238.21
Non-Profit Income         \$ 44,95.6         \$ 31,448.20           1704 1400 Non Profit Income         \$ 58.95.5         177.60           14100 Sales-Promotional/awareness products         \$ 58.95.5         177.60           In-kind donation         424.11         36.77           Sales - Promotional/awareness products (+shirts, pens, lapel pins, rubber bracelets)         230.01           Total Income         \$ 46,293.2         \$ 320,423           COST OF GOODS SOLD         \$ 275.20         \$ 45,000.2         \$ 40,200.2           1401 Cost of Goods Sold         \$ 275.20         \$ 36,200.2         \$ 30.20           2014 Cost of Goods Sold         \$ 275.20         \$ 36,200.2         \$ 31,600.1           EXPENSES         \$ 275.20         \$ 36,200.2         \$ 34,600.2         \$ 31,600.1           SOOD Bank Charges         \$ 31,000.2         \$ 34,600.2         \$ 31,600.1         \$ 32,500.2         \$ 32,500.2         \$ 32,600.2<	4002 Individual Donations		37,209.76		23,148.94
Total 4000 Non Profit Income         \$ 44,995.48         \$ 131,486.20           4100 Sales-Promotional/awareness products         589.95         177.60           In-kind donation         589.95         177.60           Sales of Product Income         20.00         30.00           Sales-Promotional/awareness products (t-shirts, pens, lapel pins, rubber bracelets)         20.00         20.00           Total Income         \$ 46,293.29         \$ 20,204.30           OSC FO GOODS SOLD         275.20         \$ 44,00           101 Clost of Goods Sold         275.20         \$ 46,00           Stoll Cost of Goods Sold         \$ 255.20         \$ 31,600.11           EXPENSES         \$ 45,964.72         \$ 136,600.11           200 Sales Tax on Promo products         8 343.60         \$ 12.00           5001 2016 Seattle Medical Forum         8 343.60         \$ 12.00           7010 Office General Administrative Expenses         1 1,555.40         \$ 10.00           7020 Office/General Administrative Expenses         1 1,555.40         \$ 10.00           7030 Promotional         \$ 2,000.20         \$ 50.00           7030 Promotional         \$ 50.00         \$ 50.00           7040 Office/General Administrative Expenses         \$ 10.00         \$ 50.00           7050 Research fund	4400 2016 Seattle Medical Forum Registration		4,200.00		
1100 Sales-Promotional/awareness products   589,55   177,60     In-kind donation	Non-Profit Income				722.95
In-linkind domation         424.11         367.77           Sales of Product Income         230.01         30.01           Total Income         \$ 46,239.02         \$ 20,202.02           CDST OF GOODS SOLD         275.02         4.00         30.00           141 Cost of Goods Sold         275.02         4.00         30.00	Total 4000 Non Profit Income	\$	44,995.46	\$	31,448.20
Sales of Product Income         20.000 cm         30.000 cm           Sales Promotional/awareness products (t-shirts, pens, lapel pins, rubber bracelets)         20.000 cm         20.000 cm           Total Income         \$ 46,239.20         \$ 20.000 cm           COST OF GOODS SOLD         275.20         44.00           Supplies & Materials - COGS         275.20         44.00           Stock of Goods Sold         \$ 275.20         \$ 36.20           Total Cost of Goods Sold         \$ 275.20         \$ 36.20           RORSS PROFIT         \$ 45,962.20         \$ 36.20           EXPENSES         3         \$ 25.00         \$ 36.40           5001 2016 Seattle Medical Forum         8,343.62         \$ 12.30           6000 Bank Charges         311.92         12.30           7010 Office Expenses         311.92         12.30           7010 Office Expenses         1,555.40         1,025.00           7020 Office/Ceneral Administrative Expenses         1,555.40         1,025.00           7030 Promotional         \$ 2,513.50         9.00           Fundraising Expense         1,555.40         9.00           7041 7030 Promotional         \$ 2,513.50         9.00           8001 Insurance         750.00         9.00           10	4100 Sales-Promotional/awareness products		589.95		177.60
Sales-Promotional/awareness products (t-shirts, pens, lapel pins, rubber bracelets)         200.00         46,239.92         32,024.39           COST OF GOODS SOLD         275.00         44.00         20.00         44.00           4101 Cost of Goods Sold         275.00         30.02         30.02           Total Cost of Goods Sold         \$ 755.00         \$ 364.28           GROSS PROFIT         \$ 8,785.00         \$ 316.60.11           EXPENSES         \$ 8,343.62         \$ 6.84           5001 2018 Seattle Medical Forum         8,343.62         \$ 12.00           6000 Bank Charges         65.95         \$ 12.00           7010 Office Expenses         65.95         \$ 12.00           7020 Office/General Administrative Expenses         1,555.40         1,025.00           7030 Promotional         1,555.40         \$ 50.00           7030 Promotional         \$ 2,966.2         \$ 74.00           7050 Research funding         5,000.00         10,000.00           8010 Insurance         75.00         10,000.00           8010 Insurance - Liability         75.00         10           Dues & Subscriptions         75.00         15.04           Labor or services donated         62.10         15.04           Total Cherry Expenses	In-kind donation		424.11		367.78
Total Income         \$ 46,239.22         \$ 32,024.39           COST OF GOODS SOLD         275.20         440           4101 Cost of Goods Sold         275.20         440           Supplies & Materials - COGS         202.28           Total Cost of Goods Sold         \$ 275.20         \$ 364.28           GROSS PROFIT         \$ 45,964.72         \$ 316.60.1           EXPENSES         \$ 45,964.72         \$ 6.85           2030 Sales Tax on Promo products         8,843.62         \$ 6.85           5001 2015 Seattle Medical Forum         8,843.62         \$ 12.83           6000 Bank Charges         311.92         123.86           7010 Office Expenses         6.95         \$ 10.25           7020 Office/General Administrative Expenses         1,555.4         \$ 1,025.90           7030 Promotional         2,366.23         \$ 95.00           Total 7030 Promotional         \$ 2,515.9         \$ 95.00           7050 Research funding         79.00         10,000.00           3001 Insurance         794.00         794.00           B001 Insurance         794.00         794.00           Labor or services donated         75.00         13.54           Taxes & Licenses         75.00         13.54           T	Sales of Product Income				30.81
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4101 Cost of Goods Sold       275.20       44.00         Supplies & Materials - COGS       320.28         Total Cost of Goods Sold       \$ 275.20       \$ 364.28         GROSS PROFIT       \$ 45.04.27       \$ 316.60.11         EXPENSES       \$ 257.20       \$ 6.84         2030 Sales Tax on Promo products       8.343.62       \$ 25.00         6000 Bank Charges       311.92       12.86         7010 Office Expenses       65.95       \$ 1.025.90         7020 Office/General Administrative Expenses       1,555.40       1,025.90         7030 Promotional       2,366.23       \$ 595.00         Total 7030 Promotional       \$ 2,513.99       \$ 595.00         7050 Research funding       5,000.00       \$ 10,000.00         8000 Insurance       794.00       \$ 744.00         8010 Insurance - Liability       794.00       \$ 744.00         9us & Subscriptions       75.00       135.94         Labor or services donated       75.00       135.94         Taxes & Licenses       75.00       135.94         Total Expenses       \$ 19,358.8       12,631.54         NET COPERATING INCOME       \$ 25.00       \$ 19,020.57         Total Other Expenses       \$ 25.00       \$ 0.00	Total Income	\$	46,239.92	\$	32,024.39
Supplies & Materials - COGS         3 2028           Total Cost of Goods Sold         \$ 275.20         \$ 364.28           GROSS PROFIT         \$ 45,964.72         \$ 31,660.11           EXPENSES         \$ 2030 Sales Tax on Promo products         \$ 6.84           5001 2016 Seatite Medical Forum         8,343.62         \$ 12.83           6000 Bank Charges         \$ 311.92         1 23.86           7010 Office Expenses         65.95         \$ 10.00           7020 Office/General Administrative Expenses         1,555.40         1,025.90           7020 Office/General Administrative Expenses         147.36         595.00           7020 Office/General Administrative Expenses         147.36         595.00           7020 Office/General Administrative Expenses         1,555.40         1,025.90           7020 Office/General Administrative Expenses         2,515.90         595.00           7020 Office/General Administrative Expenses         1,025.90         595.00           7050 Research funding         5,000.00         794.00	COST OF GOODS SOLD				
Total Cost of Goods Sold         \$ 275.20         \$ 364.28           GROSS PROFIT         \$ 45,964.72         \$ 31,660.11           EXPENSES         ************************************	4101 Cost of Goods Sold		275.20		44.00
GROSS PROFIT         \$ 45,964.72         \$ 31,660.11           EXPENSES         6.84           2030 Sales Tax on Promo products         8,343.62         6.84           5001 2016 Seattle Medical Forum         8,343.62         123.66           6000 Bank Charges         311.92         123.66           7010 Office Expenses         65.95         123.66           7020 Office/General Administrative Expenses         1,555.40         1,025.90           7030 Promotional         2,366.23         125.00           Fundraising Expense         147.63         595.00           7050 Research funding         5,000.0         10,000.00           8010 Insurance         794.00         10,000.00           8010 Insurance - Liability         75.00         135.94           Dues & Subscriptions         75.00         135.94           Labor or services donated         75.00         135.94           Taxes & Licenses         75.00         135.94           NET OFLERATIOS INCOME         \$ 26,061.1         19,028.57           TOTHER EXPENSES         \$ 26,001.2         \$ 0,000           MISCEIlaneous         \$ 25.00         \$ 0,000           Total Other Expenses         \$ 25.00         \$ 0,000           NET OTHER	Supplies & Materials - COGS				320.28
EXPENSES         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         7050 Research funding       5,000.00       10,000.00         8000 Insurance       794.00       -         8010 Insurance - Liability       794.00       -         Dues & Subscriptions       75.00       135.94         Labor or services donated       624.10       -         Taxes & Licenses       75.00       135.94         Total Expenses       \$ 19,358.8       12,631.54         NET OPERATING INCOME       \$ 26,606.1       19,028.75         Total Other Expenses       \$ 25.00       \$ 0.00         NET OTHER INCOME       \$ 25.00       \$ 0.00         NET OTHER INCOME       \$ 25.00       \$ 0.00	Total Cost of Goods Sold	\$	275.20	\$	364.28
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       595.00         Fundraising Expense       147.36       595.00         7050 Research funding       5,000.00       10,000.00         8000 Insurance       5,000.00       744.00         8010 Insurance - Liability       794.00       75.00         Dues & Subscriptions       75.00       135.94         Labor or services donated       624.10       135.94         Taxes & Licenses       75.00       135.94         NET OPERATING INCOME       \$ 26,061.4       19,028.15         Miscellaneous       25.00       100.00         NET OPICER EXPENSES       \$ 25.00       \$ 0.00         Total Other Expenses       \$ 25.00       \$ 0.00         NET OPICER EXPENSES       \$ 0.00       \$ 0.00         Total Other Expenses       \$ 25.00       \$ 0.00         NET OFILER EXPENSES       \$ 0.00       \$ 0.00         Total Other Expenses       \$ 25.00	GROSS PROFIT	\$	45,964.72	\$	31,660.11
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6000 Bank Charges       311.92       123.86         7010 Office Expenses       65.95	2030 Sales Tax on Promo products				6.84
7010 Office Expenses         65.95           7020 Office/General Administrative Expenses         1,555.40         1,025.90           7030 Promotional         2,366.23	5001 2016 Seattle Medical Forum		8,343.62		
7020 Office/General Administrative Expenses         1,555.40         1,025.90           7030 Promotional         2,366.23         595.00           Fundraising Expense         147.36         595.00           7050 Research funding         5,000.00         10,000.00           8000 Insurance         744.00           8010 Insurance - Liability         794.00         744.00           Dues & Subscriptions         75.00         135.94           Labor or services donated         624.10         135.94           Total Expenses         \$ 19,358.58         12,631.54           NET OPERATING INCOME         \$ 26,606.14         \$ 19,028.57           OTHER EXPENSES           Miscellaneous         25.00         \$ 0.00           NET OTHER INCOME         \$ 25.00         \$ 0.00           NET OTHER INCOME         \$ 25.00         \$ 0.00	6000 Bank Charges		311.92		123.86
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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           Total Expenses         \$ 19,358.58         \$ 12,631.54           NET OPERATING INCOME         \$ 26,606.14         \$ 19,028.57           OTHER EXPENSES           Miscellaneous         25.00         \$ 0.00           NET OTHER INCOME         \$ 25.00         \$ 0.00           NET OTHER INCOME         \$ 25.00         \$ 0.00	Fundraising Expense		147.36		595.00
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         Total Expenses       \$ 19,358.88       \$ 12,631.54         NET OPERATING INCOME       \$ 26,606.14       \$ 19,028.57         OTHER EXPENSES         Miscellaneous       25.00       \$ 0.00         NET OTHER INCOME       \$ 25.00       \$ 0.00         NET OTHER INCOME       \$ 25.00       \$ 0.00	Total 7030 Promotional	\$	2,513.59	\$	595.00
8010 Insurance - Liability       794.00         Dues & Subscriptions       75.00         Labor or services donated       624.10         Taxes & Licenses       75.00       135.94         Total Expenses       \$ 19,358.58       \$ 12,631.54         NET OPERATING INCOME       \$ 26,606.14       \$ 19,028.57         OTHER EXPENSES         Miscellaneous       25.00       \$ 0.00         NET OTHER INCOME       \$ 25.00       \$ 0.00         NET OTHER INCOME       \$ 25.00       \$ 0.00	7050 Research funding		5,000.00		10,000.00
Dues & Subscriptions         75.00           Labor or services donated         624.10           Taxes & Licenses         75.00         135.94           Total Expenses         \$ 19,358.58         \$ 12,631.54           NET OPERATING INCOME         \$ 26,606.14         \$ 19,028.57           OTHER EXPENSES           Miscellaneous         25.00         \$ 0.00           NET OTHER INCOME         \$ 25.00         \$ 0.00           NET OTHER INCOME         \$ 25.00         \$ 0.00	8000 Insurance				744.00
Labor or services donated         624.10           Taxes & Licenses         75.00         135.94           Total Expenses         \$ 19,358.58         \$ 12,631.54           NET OPERATING INCOME         \$ 26,606.14         \$ 19,028.57           OTHER EXPENSES           Miscellaneous         25.00         \$ 0.00           NET OTHER INCOME         \$ 25.00         \$ 0.00           NET OTHER INCOME         \$ 25.00         \$ 0.00	8010 Insurance - Liability		794.00		
Taxes & Licenses         75.00         135.94           Total Expenses         \$ 19,358.58         \$ 12,631.54           NET OPERATING INCOME         \$ 26,606.14         \$ 19,028.57           OTHER EXPENSES         25.00         \$ 25.00           Total Other Expenses         \$ 25.00         \$ 0.00           NET OTHER INCOME         \$ 25.00         \$ 0.00	Dues & Subscriptions		75.00		
Total Expenses         \$ 19,358.58         \$ 12,631.54           NET OPERATING INCOME         \$ 26,606.14         \$ 19,028.57           OTHER EXPENSES         25.00         \$ 25.00           Total Other Expenses         \$ 25.00         \$ 0.00           NET OTHER INCOME         \$ 25.00         \$ 0.00	Labor or services donated		624.10		
NET OPERATING INCOME         \$ 26,606.14         \$ 19,028.57           OTHER EXPENSES           Miscellaneous         25.00           Total Other Expenses         \$ 25.00         \$ 0.00           NET OTHER INCOME         -\$ 25.00         \$ 0.00	Taxes & Licenses		75.00		135.94
OTHER EXPENSES           Miscellaneous         25.00           Total Other Expenses         \$ 25.00         \$ 0.00           NET OTHER INCOME         \$ 25.00         \$ 0.00	Total Expenses	\$	19,358.58	\$	12,631.54
Miscellaneous         25.00           Total Other Expenses         \$ 25.00         \$ 0.00           NET OTHER INCOME         -\$ 25.00         \$ 0.00	NET OPERATING INCOME	\$	26,606.14	\$	19,028.57
Total Other Expenses         \$         25.00         \$         0.00           NET OTHER INCOME         -\$         25.00         \$         0.00	OTHER EXPENSES				
NET OTHER INCOME -\$ 25.00 \$ 0.00	Miscellaneous		25.00		
	Total Other Expenses	\$	25.00	\$	0.00
NET INCOME \$ 26,581.14 \$ 19,028.57	NET OTHER INCOME	-\$	25.00	\$	0.00
	NET INCOME	\$	26,581.14	\$	19,028.57

#### **MOWAT-WILSON SYNDROME FOUNDATION**

# 2017 BUDGET (with 2016 comparison)

	2017	2016
INCOME		
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
TOTAL NONPROFIT INCOME	\$ 144,440.55	\$ 45,964.72
EXPENSES		
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 \$ 833.70 \$ 100.00 \$ - \$ 75.00	\$ 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
TOTAL NONPROFIT EXPENSES	\$ 142,538.64	\$ 19,383.58
NET INCOME	\$ 1,901.91	\$ 26,581.14







#### **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 <a href="mailto:conference@mowat-wilson.org">conference@mowat-wilson.org</a>

#### 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.



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



