

2015 NON-PROFIT REPORT



MANITOBA NEUROFIBROMATOSIS SUPPORT GROUP



*Keeping you **in**formed!*



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Message from the President



It has been just over ten years since a few families came together to offer mutual support as their children faced the challenges that come with a diagnosis of Neurofibromatosis (NF). As the only organization in Manitoba dedicated to offering programs and support and furthering awareness of NF, it has been a challenging and rewarding period of growth.

“Without courage we have no fear; without fear we have no courage” Four years ago, a young woman named Courtney Willoughby was inspired by these words from Reggie Bibbs, founder of the *“Just Ask”* Foundation to find her own courage in the face of NF. This October, these passionate advocates for NF awareness were reunited as our Keynote Speakers at the first MBNF Empowerment Symposium. Participants also heard about the latest research into Neurofibromatosis. An Occupational Therapist and a Life Coach each spoke about ways to empower those living with NF to reach their greatest potential. We are thankful to have been able to host this event to help others like Courtney face their fears and find new courage.

In addition to organizing our first symposium, we continued to offer a full slate of fundraising and member events that you will see highlighted in this report. Thank you to all of our volunteers and supporters who ensure that MBNF is able to continue to support our mission.

Thanks to a generous bequest to our organization, we established the Manitoba Neurofibromatosis Support Group Endowed Fund with the Children’s Hospital Foundation of Manitoba. This lasting legacy will initially generate a modest income stream for our activities. Growth of this fund in the future will open opportunities to support research into NF. Please consider a contribution to this fund now or as part of your estate planning.

On behalf of all of the members and Board of Directors of MBNF, I would like to express my thanks our Executive Director, Tracy Gregorash for her work on behalf of our organization. She consistently goes above and beyond for all of us.

Respectfully submitted,

Nancy Anderson
President, MBNF

Message from the Executive Director

As I reflect on another year of our group's activities, it is hard not to mention how truly important our friends are. It was 10 years ago, Christa and I met for coffee to meet the first family either of us had met living with NF in Manitoba! That friendship blossomed, and since then numerous individuals and families, affected by NF in Manitoba have also grown as friends. That snowballed into a supportive network of caring individuals, families, volunteers and corporations who have generously provided the inspiration and strength to help us grow into the established Manitoba Neurofibromatosis Support Group we are today, providing help to over 100 families in Manitoba who need our assistance each year.



Our priorities are to provide a supportive place to connect, to raise funds for resources and increase neurofibromatosis awareness throughout the province. In 2015, we welcomed new families, hosted get-togethers, developed new fundraisers and celebrated hosting the first NF Symposium in the Province. We have connected with the other provincial groups that do exist and helped those in provinces where the support is not available. We know these programs and priorities would not have been met without the support of our friends and communities.

It is critical we continue our work and investments into providing more specialized medical care for our members. There are currently few doctors who feel comfortable treating NF patients, there is no NF Clinic or Health care navigator for the variety of symptoms that arise from this progressive disorder. Some members have been diagnosed late in life and others were not even told their child had symptoms of NF. We can only assume doctors hesitate to make the diagnosis because of the lack of information and resources available. We need to reach all the doctors in Manitoba, so that they know, they can at least provide a supportive place for those diagnosed to turn to.

We are hopeful, when you look through this year's annual report, you will meet some of our amazing friends and supporters and friends of MBNF and know how valued you are. We treasure all of our friends and know the difference they can make.

With anticipation,

Tracy Gregorash
Executive Director

ABOUT US...

Mission

The Manitoba Neurofibromatosis Support Group (MBSG) is committed to improving the lives of individuals and families affected by Neurofibromatosis (NF). MBSG provides support, promotes awareness and works towards building funding for scientific research to improve medical treatment - and ultimately to find a cure!

Vision

MBSG envisions lives freed of physical and emotional pain caused by Neurofibromatosis.

Action

MBSG provides confidential support and distributes information about NF to members, families, health care professionals, and various organizations. We publish an annual newsletter and hold two Support Group Meetings each year. We host an up-to-date website and a discussion forum on Facebook. We also connect through Twitter and YouTube. We host a variety of fundraising events and get-togethers in support of those living with neurofibromatosis and we continually look for ways to advance the awareness of NF.

AWARENESS...

NF Awareness Month is May!

In 2014, Bill 214 was passed in the Manitoba Legislature (sponsored by Mrs. Leanne Rowat), which proclaims the month of May each year as Neurofibromatosis (NF) Awareness Month. In 2015, MBSG celebrated further success as Brandon Mayor Rick Chrest proclaimed Sunday, May 17, 2015 as "NF Awareness Day" in the city of Brandon. On May 22, 2015, several MBSG members were able to meet with Manitoba Health Minister, Honourable Sharon Blady, MLA to discuss the successes, challenges and needs of MBSG. With no nationwide support group and other provincial NF support groups closing their doors, MBSG is reaching out to friends in the political and public health sector to ask for support to ensure that the needs of those with NF will be adequately met. Issues such as transition from child to adult care, multidisciplinary medical needs, and educational challenges for children with NF were all discussed, as well as our dream of a provincial NF Clinic, NF Patient Care Coordinator, and possible funding to offset costs for participation in NF research. The meeting was an opportunity to build relationship with our Health Minister and continue to promote awareness!

Board of Directors

Meet the men and women who currently serve as the Board of Directors for MBNF. We appreciate their spirit of generosity, and their gifts of time and talent to make MBNF a strong organization.



(President) **Nancy Anderson** is married to Blair and they have an adult son Neal. Nancy works at The Manitoba Museum. She also volunteers with the Manitoba Crafts Museum and Library, the Winnipeg Fringe and as a staff representative on The Manitoba Museum board. In her spare time she enjoys quilting, knitting and biking with their dog Chloe.



(Past President) **Christa DeGagne** is married to Corey and they have 2 girls, Kiara is 13 and Kaylee is 7. Christa works at the University of Manitoba and in her spare time likes staying active and having fun with family.



(Executive Director) **Tracy Gregorash** lives in Minnedosa and works out of her home, where she oversees the daily operations of the Manitoba NF group. Tracy and Troy have 2 teenaged sons and the youngest has NF. She enjoys running and playing badminton.



(Secretary) **Becky Penner** is the only one in her family who has NF. She has two older sisters and a dachshund named Oliver. She enjoys listening to music, making cards and spending time with her family. She is currently working in administration at Executive Nursing.



(Director) **Troy Gregorash** is married to Tracy; they have 2 children, Levi 17 and Seth 15. They live in Minnedosa where Troy works for Manitoba Hydro. He enjoys snowmobiling and playing hockey.



(Director) **Lyndon Demers** lives in Winnipeg and where he works for Skybridge Americas and Wal-Mart. He enjoys spending quality time with family and friends. He enjoys playing and watching hockey, watching football and playing video games. He also enjoys some water sports and camping.



(Director) **Brenda Marion-Gerula** is married to Eddie; they have 4 children Ethan and Julian 7, Aidan 6 and Abigail 3. They reside in Winnipeg. Brenda and her husband enjoy running together. Brenda loves to run long distance and has completed numerous half marathons. She operates a home daycare.

(Director) **Corrine Bobrowich** is married to Brad and they have 2 children, Brady (8) and Brooke (5). They live in St. Andrews, MB. Her son, Brady has NF 1, being diagnosed at 5 months of age. She is a Physiotherapist and she and her husband own their own clinic (Steelcity Physiotherapy) in Selkirk, MB. In her spare time, she enjoys camping/ cottaging, playing volleyball, jogging and spending time outdoors.



(Director) **Kathleen Demers** has been a member since 2007, Kathleen has enjoyed almost 10 years of activities and support thru MBNF. Kathleen has been married for 32 years, is the proud mother of 3 adult children, 1 daughter-in-law and 1 beautiful granddaughter. She keeps busy working full-time as an elementary school secretary. In her spare time, Kathleen enjoys time with her family and friends, quilting for charity raffles and spending time enjoying MBNF activities.

(Director) **Suzanne Lendvoy** is married to Robin Lendvoy. They have two sons, Isaak (16) and Nikolas (19). Isaak was diagnosed with NF1 when he was 7 years old, although some of the signs were present much sooner. The Lendvoys live in Regina, where Suzanne works as an occupational therapist. Since there is no formal support network for those with NF in Saskatchewan, Suzanne reached out to neighbouring provinces, and feels lucky to have found the MBNF group.



(Director) **Melissa Kinasevch** resides in Winnipeg with her husband Zenon, son Ivan and a one year old Labrador named Sadie. In her spare time, she enjoys traveling, biking, cooking, baking and taking Sadie for long walks.

(Director) **Doreen Loewen** moved to Brandon a number of years ago to be closer to her family. She has two children, a son-in-law, two grandchildren, and runs a business doing bookkeeping for small businesses. When Doreen is not spending time with her grandchildren, she enjoys dancing, golfing and hanging out with friends. She was recently introduced to kayaking and is totally hooked enjoyed paddling on a few lakes and rivers this past summer.



SUPPORTIVE NETWORK OF FRIENDS...

Symposium

The first NF Empowerment Symposium was held at the Victoria Inn in Winnipeg on October 18, 2015. It was well attended by members of the support group, as well as several guests from the medical community. The speakers were excellent and presented a balance of educational material and empowerment content, and participant surveys reported a high level of satisfaction with this event!

A primary objective for the MBNF group is to promote networking and relationship building within the NF community – the symposium was successful in this regard as attendees had opportunity to visit together, share a meal together, and participate at the Annual General Meeting held the following day. The medical and scientific professionals in attendance were enthusiastic about the event, and worked collaboratively during the Question/Answer session.



Thank you to all who served on the planning committee, to our generous financial supporters, and our guest speakers for making this inaugural event a great success!

Guest speakers at the Symposium were:

- Suzanne Lendvoy (Occupational Therapist, Regina, SK) – Sensory Processing Disorder and related NF LD's (Learning Disorders)
- Dr. Jan Friedman (University of British Columbia, Medical Geneticist) – NF Basics and Plexiform Tumours
- Dr. Issai Vanan (Pediatric Neuro-Oncology, Cancer Care Manitoba) – Clinical Trials and NF Research Update
- Desiree Sher (Executive Director of BCNF, author, Lifecoach, Vancouver, BC) – Refuse to Sink – Living Your Best Life Possible
- Courtney Willoughby (blogger, student, Red Deer, AB) – Keynote Speaker
- Reggie Bibbs (Just Ask Foundation, Houston, TX) – Keynote Speaker

Meetings

MBNF hosts two meetings each year to give more opportunity for everyone to attend. We hold our spring meeting in Brandon and our fall AGM in Winnipeg. Our members reside all across Manitoba. We also have people travel from Saskatchewan, as they currently have no support in their province for NF. Meetings are typically 2 hours in length, with another hour of visiting afterwards. This gives our members an opportunity to network with each other, learn of new MBNF activities and share their ideas and needs from our group.

Website

MBNF is proud to have a very modern website where we post our mission, events and member stories for people to use as a reference. Our website is often a first point of contact for folks in search of support, so we work hard to keep our best foot forward here! The website also enables us to keep reference materials and event updates available 24/7! We value our members and want to keep everyone informed of our events and fundraising efforts. We also have a DONATION opportunity available on the website to help with fundraising.

Please see our website to learn more about Neurofibromatosis, our group's activities and member's stories.

<http://www.mbnf.ca>

Facebook

This page is dedicated to those living with NF as well as their families and friends. It is a great way for everyone to participate in exchanging stories, ideas and information! It helps us reach a wider audience to create awareness about NF, our group and updates on the various events. Please check it out and be sure to 'like'!

MBNF also hosts a Virtual Coffee Group for its members. This is a private page reserved for those who have NF and their immediate family members. It is intended to be a safe place for people with NF to be comfortable to discuss their challenges, struggles and triumphs with other members. The Coffee Group is a lovely gathering of friends, and the discussion is lively and uplifting!

Database

MBNF has been working to establish a database for group members. This platform enables us to communicate more effectively with our group, integrate our events and fundraising with our website, and perhaps most importantly, create a credible, quantitative measure of the support services we offer. Ultimately, we envision a Patient Care Coordinator at the provincial level who will coordinate medical and other support services for those with NF, and in order to strengthen our voice, quantitative, empirical data must be available to substantiate our request. As MBNF group membership continues to grow, we are committed to gathering meaningful data that will be used to advocate for best patient care, and contribute to meaningful research.

EVENTS...

Let's Dance for NF

The Let's Dance for NF event was cancelled in 2015, but is planned for May 14, 2016 at the Victoria Inn in Brandon, MB! The evening involves a Dance Showcase, talented MC's and DJ, plus great prizes and an auction! All are welcome! Check our website for details!

Manitoba Marathon – Charity Partner

In 2015 we were honored to be a charity partner with the Manitoba Marathon held in Winnipeg! Approximately 30 runners gathered and participated in various events (including the Super Run, 10k, relay, half marathon, and full marathon) wearing the MBNF bib! We were thrilled to have the 2nd place female marathon runner wearing an MBNF bib!



Congratulations to all those who participated in the event, including runners, volunteers at the NF booth at the Expo and of course, our wonderful cheer team!



Run with Me - Minnedosa



On Saturday, June 6th, MBNF hosted its 9th annual Run 4 NF in Minnedosa. This 5km timed race begins and ends at the Minnedosa Beach Pavilion and has a scenic route through town. In 2015, there were approximately 80 race participants and volunteers. Registered runners received a free NF t-shirt! We're looking forward to celebrating our 10th annual run, which is schedule for June 2016, and planning some extra special celebrations! Come join us!

Run with Me – Lockport River's Edge Run



The inaugural Lockport Run was held on September 19, 2015. The Run was well attended and offered 5k, 10k, Half Marathon and 30k distances. By all accounts, this event was an extraordinary success! We've got our eye on the 2016 run, which is slated for September 17, 2016!

Annual Picnic

Every August, MBNF group members meet on a Sunday afternoon at a park for an afternoon of food, games and fun. The gathering typically has 30 – 50 people, but was rained out last year! The 2016 Annual Picnic (scheduled for August 20) will have an alternate location in case of rain! It is a wonderful opportunity to interact with other NF families and friends whose support is invaluable!



Santa Picture Day

Santa Picture Day is an extremely appreciated third Party Fundraiser for our group. We are so blessed to have Photography by Dale, from Brandon, choose to take time from their busy schedule to consider our group every winter. This was their 4th Santa Picture Day. Each year, Bree, Dale's wife and Lindsay (MBNF member) dress up as elves and usher the families to meet Santa for a high quality image keepsake. You can even order these as Christmas cards. This past annual event was their biggest success yet, raising \$1618.55 for MBNF! A great benefit of this event is to raise awareness about NF and our group. We are so thankful for Dale and Bree Schappert of Brandon.

Be sure to check out past events in our picture gallery on our website www.mfnf.ca !



NF Camp

In partnership with the Children's Tumor Foundation, Camp Kostopulos hosts 2 weeks of specialized NF camp in Salt Lake City, UT. It boasts a variety of activities such as swimming, horseback riding, camp fires, rope course, climbing wall, fishing and day trips. Everyone attending the camp is affected by NF, which creates an atmosphere of compassion and understanding, and an opportunity to build friendships with those who live with similar issues. The camp is a fantastic opportunity for young people who are living with NF, not only for the physical adventure, but also for the social support and confidence they gain that lasts well beyond the duration of the camp. In 2015, the Winnipeg Goldeyes Field of Dreams Foundation awarded \$2,000 to MBNF to provide a scholarship to attend this amazing camp. Our support group was able to help three other teens join them on this adventure.



SPOTLIGHT!

Just Ask Foundation

Founded by Reggie Bibbs, the Just Ask! Foundation is a non profit organization which helps people affected by NF lead more productive and satisfying lives. The Just Ask! Foundation is located in Houston, Texas, and includes a website, Facebook page, shop (for Just Ask! T-shirts), and includes several helpful links about NF and NF Treatment. MBNF was fortunate to have Reggie as one of our keynote speakers at the 2015 Symposium in Winnipeg, and as always, we were encouraged and uplifted by our friend.

Check out justaskfoundation.org for more information!



2015 Volunteer of the Year – Lyndon Demers



Each year, the MBNF Support Group honors an individual who contributes to our local NF community in a remarkable way. While *all* contributions are important, this award seeks to acknowledge the outstanding personal contributions of an individual whose actions, words, and deeds build others up and enhances the overall spirit of our community.

The recipient of the 2015 Volunteer of the Year Award has a very special kind of energy and brings a unique enthusiasm to our group! He is passionate about promoting awareness, excited to be a director, proud of MBNF, and demonstrates active volunteerism (both for our group and others). He has been a member of the MBNF Support Group for many years, and currently serves as an MBNF Board Member. In the past, this young man has organized successful fundraising events, and continues to participate and volunteer at every event he can!

I would also like this opportunity to thank each one of you who gives of your time and talent to participate in the MBNF Support Group. This is a group built by volunteers who seek to support those who walk this journey. The task feels daunting at times, but as Helen Keller has said,

“The world is moved along, not only by the mighty shoves of its heroes, but also by the aggregate of tiny pushes of each honest worker.”

Thank you for your support!

We rely on the generous financial support of our community to sustain our services. Thank you to all our donors and funders whose gifts made a difference to the lives of many.

Our Financial Statement

The following charts represent our current Income and Expenses. More specific financial information is available upon request. The Board has hopes of creating an additional part-time position to assist with administration and marketing. Currently the Executive Director carries all the responsibilities of administration, marketing, event planning, donation acknowledgment, website maintenance, social media, meeting agendas and providing moral support for NF members.

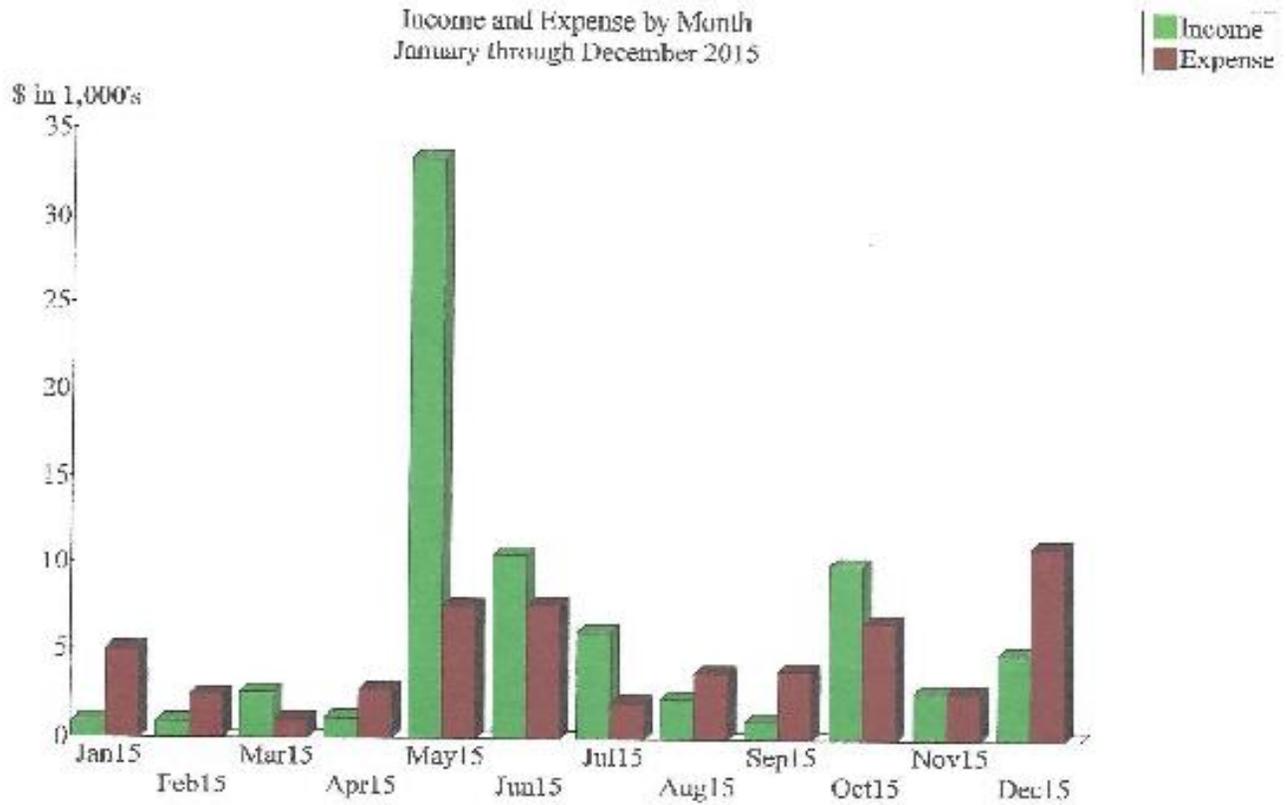
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Accrual Basis

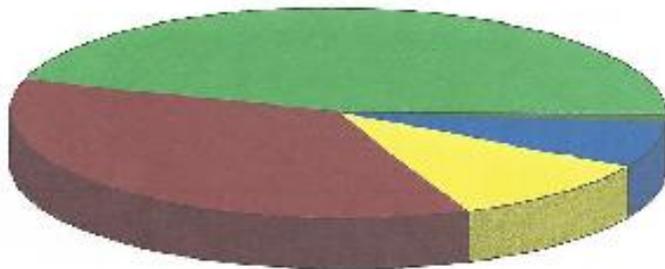
MBNF Support Group Inc.
Profit & Loss
 January through December 2015

	Jan - Dec 15
Ordinary Income/Expense	
Income	
Event Income	27,565.79
Gifts - not receipted	34,672.43
Gifts - tax-receipted	5,165.73
Gifts from other charities	8,230.08
Merchandise Sales	567.00
	76,201.03
Total Income	76,201.03
Expense	
Advertising and Promotion	5,750.81
Awards and Grants	5,983.01
Depreciation Expense	1,401.59
Equipment	878.78
Fundraising Event Expenses	6,278.38
Honorariums & Gifts	450.89
Meeting Expenses	10,120.09
Membership & Association fees	25.00
Miscellaneous	190.95
Office Expenses	
Commissions - online donations	34.99
Transaction fees	225.37
Office Expenses - Other	3,963.50
	4,223.86
Total Office Expenses	4,223.86
Operating Costs	
Executive Director costs	13,000.00
	13,000.00
Total Operating Costs	13,000.00
Professional Fees	1,312.17
Program Support	5,366.89
Promotional Materials	995.29
Volunteer appreciation	83.75
	56,061.46
Total Expense	56,061.46
Net Ordinary Income	20,139.57
Net Income	20,139.57

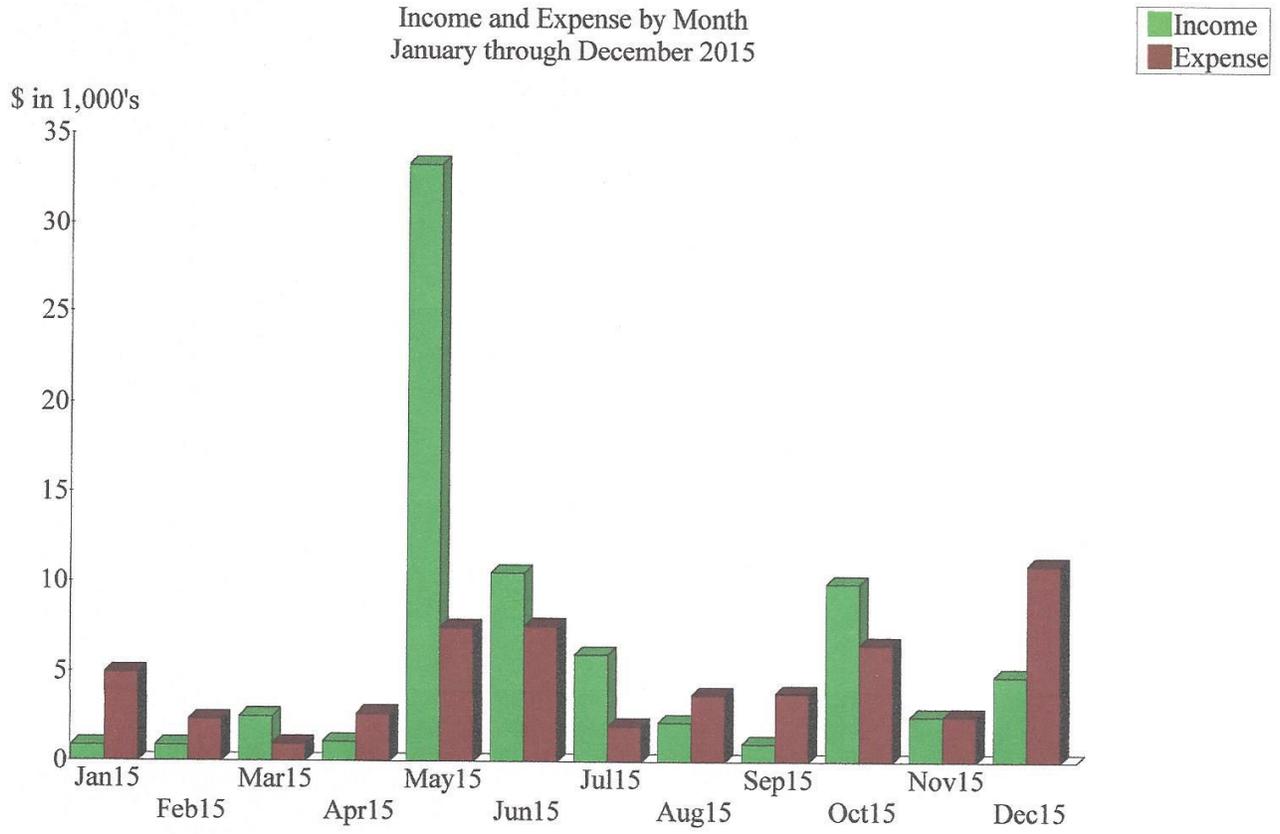


Income Summary
January through December 2015

Gifts - not receipted	45.50%
Event Income	36.18
Gifts from other charities	10.80
Gifts - tax-receipted	6.78
Merchandise Sales	0.74
Total	\$76,201.03

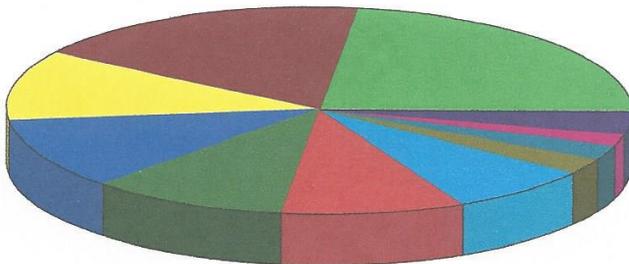


By Account



Expense Summary
January through December 2015

Operating Costs	23.19%
Meeting Expenses	18.05
Fundraising Event Expenses	11.20
Awards and Grants	10.67
Advertising and Promotion	10.26
Program Support	9.57
Office Expenses	7.53
Depreciation Expense	2.50
Professional Fees	2.34
Promotional Materials	1.78
Other	2.91
Total	\$56,061.46



By Account