SUMMARY

Mission
Support everyone affected by Waldenstrom's macroglobulinemia while advancing the search for a cure.

Contact Information

Primary Address
6144 Clark Center Avenue
Sarasota, FL 34238-

Alternate Address
6144 Clark Center Ave.
Sarasota FL 34238

Phone
941 927-4963

Email
office@iwmf.com

Website
www.iwmf.com

Facebook
waldenstroms.support/

Twitter
wmiwmf

General Information

Nonprofit
The International Waldenstroms Macroglobulinemia Foundation Inc

Organization Does Business As (DBA)
International Waldenstrom's Macroglobulinemia Foundation
IWMF
<table>
<thead>
<tr>
<th>Supported Organization</th>
<th>International Waldenstrom's Macroglobulinemia Foundation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tax Exempt Status</td>
<td>Public Supported Charity</td>
</tr>
<tr>
<td>Incorporation Year</td>
<td>2002</td>
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<tr>
<td>State Charitable Solicitations Permit</td>
<td>Yes Nov 2017</td>
</tr>
<tr>
<td>State Registration</td>
<td>Yes Jan 2018</td>
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</table>
Impact Statement

Highlights:
- Funded 11 Young Investigators (researchers who submitted promising proposals related to our disease) to travel to the International Workshop on Waldenstrom's Macroglobulinemia in the Netherlands.
- Approved funding for 3 research projects that received the highest marks from our independent review panel, plus a 4th that extended an important and promising project already underway. In total, awarded $1.7 million in research grants.
- Sent out a new LLS-IWMF Research Roadmap Request For Proposals plus a new RFP focussed on Amyloidosis in WM.
- Record breaking Education Forum attendance
- Launch of new/revamped online discussion forum, IWMF-Connect

Goals:
- Approve funding for 5 research projects that received the highest marks from our independent review panel.
- Increase membership/reach more patients and caretakers.

Needs Statement

Our top needs include:
1. Research donations to enable us to aggressively pursue the IWMF-LLS Strategic Research Roadmap to help find better treatments and ultimately a cure
2. Member Services donations to enable us to educate patients, family members and medical professionals about WM
3. Provide support so no one feels like they are alone
4. Volunteers to enable us to best serve our members while conserving cash to support Research and Member Services
5. Estate gifts of any size

Background Statement

The IWMF was founded by Arnold Smokler, a retired pharmacist who was diagnosed with WM in 1994. Finding little information available about the disease and no organized support group, Arnie started a newsletter that consisted of letters written by patients about personal experiences with the disease and with treatment therapies. From colleagues and contacts within the health professions, Arnie had access to professional journals, publications, and studies. Soon he expanded the scope of the newsletter by locating and publishing creditable information on WM, albeit in a very limited way. Arnie was careful to always reference his sources, and the newsletter earned respect among health professionals and the readership alike.

Gradually the number of members increased from doctor referrals and word-of-mouth. By September 1995 a monthly newsletter was being mailed to 125 patients. In September 1996, shortly after the first patient conference, the IWMF gained IRS approval as a not-for-profit organization under the IRS code, section 501(c)(3).

Today, the IWMF:
- has a worldwide membership of over 8,000, with Support Groups and affiliate organizations in virtually every continent
- provides support to patients and their caregivers
- enables patients to communicate with one another
- sponsors WM educational forums featuring prominent physicians and researchers
- publishes booklets on WM and its treatment
- supports research aimed at ultimately finding a cure for WM
- Since 1999, the IWMF has invested over $10 Million dollars in research on our disease.
Statement from the Board Chair

Statement from the CEO/Executive Director

Areas Served

AK
AL
AR
AZ
CA
CO
CT
DE
FL
FL- Charlotte
FL- DeSoto
FL- Hardee
FL- Hillsborough
FL- Lee
FL- Manatee
FL- Pinellas
FL- Sarasota
GA
HI
IA
ID
IL
IN
KY
LA
MA
MD
ME
MI
MN
MS
MT
International
National
NC
ND
NE
NH
NJ
NM
NV
NY
OH
Other
OK
OR
PA
RI
SC
SD
State Wide
TN
TX
UT
VA
VT
WA
WI
WV
WY
AK
AL
AR
AZ
CA
CO
CT
DE
FL
FL- Charlotte
FL- DeSoto
FL- Hardee
FL- Hillsborough
FL- Lee
FL- Manatee
FL- Pinellas
FL- Sarasota
GA
HI
IA
Currently, the IWMF has its headquarters in the USA, and has affiliate organizations in Canada, Europe, and Australia and partners with many organizations worldwide to assist in providing services to its members. These organizations help us better meet our members needs. These organizations: provide support, in their respective countries, to Waldenstrom's patients, their families, and others with an interest in the disease; provide country-specific information and/or educational programs to address patient concerns; promote and support IWMF research leading to a cure.

Service Categories

| Primary Organization Type | Diseases Disorders & Medical Disciplines |
Member Services

Description
Member Services encompasses a wide variety of services oriented toward supporting and educating patients and caregivers. Some of these services include:

- Annual Educational Forum: Held in different locations across the US, this is the premier event for patients to connect and learn. The Ed Forum includes new patient sessions along with more advanced presentations on treatment and research from the top WM specialists in the world.

- Info Packs: Packets sent to newly diagnosed patients including Fact Sheets, resources on support groups and a "Lifeline" of volunteers who can speak to their experiences with various treatments and/or symptoms, DVDs of Ed Forum presentations, and more.

- Publications: An assortment of book, booklets, etc. on WM and topics like reading blood work, treatment options, and more written by physicians, translated into multiple languages (including Spanish, French, Chinese, and Italian) and available at no charge as downloadable PDFs or in hard copy.

Budget
$810,000.00

Category
Program Linked to Organizational Strategy
Yes

Population Served
People/Families of People with Cancer

Short Term Success
Because this program encompasses a number of projects, success really varies based on specific project. One great example of short-term success is our most recent Ed Forum, which took place in Providence, RI early June 2016. We had record attendance (310) and record ratings from attendees, who overall rated the event 4.8 out of 5 --none ranked the event below a 4.

Long Term Success
In the 1990s, the IWMF was founded, there simply was no one place for WM patients to go. Many physicians hadn't heard of the disease, and with less than 1,500 cases diagnosed annually in the US, chances of meeting another WM patient were slim. For over 20 years, through Member Services, IWMF has created a community of close to 6,000 in the US and close to 8,000 internationally, many of whom communicate regularly by participating in IWMF-Talk, our social media accounts, and by submitting to our quarterly newsletter, The Torch.

Program Success Monitoring
We look at number of Info Packs sent out, number of site visits, number of publication downloads, support group attendance, attendee ratings of events like the Ed Forum, and more to see how many patients we are reaching, how many and which services they are using, and how they feel about these services.
Program Success Examples

The success of this year's Ed Forum is a great example; better are the emails, calls, Facebook comments, etc which we receive regularly from patients and caregivers thrilled to have found a reliable source of information about this rare disease, for example:

"I am so excited watching just a small portion of what you sent to me re Waldenstrom's that I hate to stop to make dinner. I plan to watch at least one of the lectures every day...if not more. Dr. Joseph Mikhael's opening talk is so interesting and full of information that I can't imagine how much more there is to know! Thank you SO much! I will let you know how I progress with what I'm learning. Thanks again." - Email, May 2016

"Would not have been able to make it if it weren't for the IWMF -- Love their yearly Ed Forums. The talk list is a great source of people who have this rare cancer and you can always find someone who is so full of wisdom." - Christine Bentley, Facebook review, March 7, 2015
Research

Description
WM is considered an orphan disease, meaning there is no government funding for research and limited incentive or opportunity for pharma companies to study or develop treatments for WM. Through our research program, we provide grants for medical professional and scientists working in topics relevant to treating or curing WM. Together with the Leukemia Lymphoma Society, we developed a Research Roadmap outlining four key topics believed by top WM specialists to be integral to treating and or curing WM. Research proposals are evaluated by our Scientific Advisory Committee to ensure they fit within this Roadmap, and then ranked, with top proposals considered for multiyear funding.

Budget
$826,805.00

Category
Program Linked to Organizational Strategy
Yes

Population Served
People/Families of People with Cancer

Short Term Success
For short term success, we look at things like the response rate to our request for proposals, the quality of proposals based on our Scientific Advisory Committee scores, and the progress reports submitted every 6 months by researchers. This year, we received research proposals from around the globe of unprecedented quality. We were able to approve over 1.7 million dollars of funding for four projects, including 3 new projects and the continuing of an ongoing project.

Long Term Success
Our research program has helped draw attention to a disease which, prior to the past decade or so, had been virtually unstudied. Our grants sponsored the project that discovered the MY88 mutation--a project which was at risk for being shut down due to lack of funding. This discovery was crucial to the development of Ibrutinib, the first therapy approved specifically to treat WM, which was approved by the FDA in January 2015.

Program Success Monitoring
We look at number of responses to RFPs, quality of responses, mandatory six month progress reports from sponsored researchers, and publication of papers, etc from sponsored researchers.

Program Success Examples
Long term, the best examples of success are findings like the discovery of MY88--discoveries which contribute to the development of treatments and open new possibilities for curing WM. WM patients are living longer thanks to these new and improved treatments.
MANAGEMENT

CEO/Executive Director

CEO/Executive Director
Mr. Carl Harrington
CEO Term Start
Jan 2013
CEO Email
carlh@comcast.net

Experience
Carl was diagnosed with WM in 2006 and has remained on “watch and wait” with smoldering WM. Carl received a BA from Hamilton College and an MA from Brown University. After earning an MBA from the Wharton School of the University of Pennsylvania, he worked for several leading marketing companies and since 1999 has had his own marketing consulting firm.

Carl is in his second term on the IWMF Board of Trustees. Having previously served as IWMF Vice President for Fundraising, Carl is currently the President of the IWMF. He resides in center city Philadelphia with his wife, Elly Levie, and is active in the PA Support Group.

Senior Staff

Dave Benson
Senior Development Officer
Sara McKinnie
Events Coordinator
Brian Miller
Major Gifts Officer
Rikki Miller
Development Manager
Jennifer Silva
Operations Manager

Staff & Volunteer Statistics

Full Time Staff 4
Part Time Staff 0
Staff Retention Rate % 100
Professional Development No
Contractors 2
Volunteers 20
Management Reports to Board Yes
CEO/Executive Director Formal Evaluation No
Senior Management Formal Evaluation No
NonManagement Formal Evaluation No

Collaborations
The IWMF partnered with the Leukemia & Lymphoma Society (LLS) to sponsor a Strategic Research Roadmap Conference in New York City in May 2015, and together developed a strategic guide used by our Scientific Advisory Committee to request and evaluate research proposals based on four identified focus topics:

- Signaling – What pathways do WM cells use for communication?
- Immunology/immunotherapy – How can we better use our own immune system to fight WM?
- Tumor microenvironment – How does the bone marrow/tumor environment affect WM cells?
- “Omics” – What else can we learn about genomics, epigenomics, and mutations in WM cells?

Other collaborations include the International Workshop on Waldenstrom’s Macroglobulinemia, which is held in collaboration with Dana Farber, Hematon, and IWWM and a partnership with the Leukemia Research Foundation to provide more support group opportunities for members.
GOVERNANCE

Board Chair

<table>
<thead>
<tr>
<th>Name</th>
<th>Affiliation</th>
<th>Status</th>
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<tbody>
<tr>
<td>Mr. Carl Harrington</td>
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Board Co-Chair

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<thead>
<tr>
<th>Name</th>
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<th>Status</th>
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<tbody>
<tr>
<td>Mr. Michael Sesnowitz</td>
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Board Members

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<tr>
<th>Name</th>
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<tr>
<td>Stephen Ansell MD</td>
<td>Scientific Advisory Committee</td>
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<tr>
<td>Peter DeNardis</td>
<td>University of Pittsburg</td>
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<tr>
<td>Beverly Docteur</td>
<td>CPA</td>
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<tr>
<td>Marlyn Friedlander</td>
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<td>Carl Harrington</td>
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<tr>
<td>Sue Herms</td>
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<td>Marcia Klepac</td>
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<tr>
<td>Robert A Kyle MD</td>
<td>Mayo Clinic</td>
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<tr>
<td>Mrs. Elena Malunis</td>
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<tr>
<td>Barry Nelson</td>
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<td>Linda Nelson</td>
<td>Community Volunteer</td>
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<tr>
<td>Michael Sesnowitz</td>
<td>VP For Fundraising</td>
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<tr>
<td>Mr. Guy Sherwood MD,</td>
<td>VP of Research</td>
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<tr>
<td>CCFP, FCFP, FAAFP</td>
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<td>Lisa Wise</td>
<td>Community Volunteer</td>
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Board Demographics - Ethnicity

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<td>African American/Black</td>
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<td>Asian American/Pacific Islander</td>
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<td>Caucasian</td>
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<td>Hispanic/Latino</td>
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<tr>
<td>Native American/American Indian</td>
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<td>Other</td>
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Board Demographics - Gender

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<tr>
<td>Female</td>
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Governance

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<td>Board Term Limits</td>
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<td>Board Orientation</td>
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<td>Number of Full Board Meetings Annually</td>
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<td>Board Self-Evaluation</td>
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<td>Written Board Selection Criteria</td>
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<td>Percentage of Board Making Monetary Contributions</td>
<td>100</td>
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<td>Percentage of Board Making In-Kind Contributions</td>
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<tr>
<td>Constituency Includes Client Representation</td>
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Comments

**Governance Comments by Organization**
All officers and trustees are unpaid, and all contribute enormously to the organization, personally calling donors, presenting to corporate sponsors, creating content for the website, publications, social media, etc, managing IT, and much more. The vast majority are either patients or caregivers of patients--IWMF is an organization run by the community it serves, one whose leadership is deeply and personally connected to the efforts and mission of the organization.

Regarding meeting minutes:

- Our board numbers fluctuate--last fiscal year, for example, we had 14 members, then only 11 when several stepped down for health reasons, and now we're back up again to 13.

- Because we have fewer board meetings, most are scheduled to last 2+ days, so there's actually more than one date for each (again, our minutes break down what happened which day--attendance numbers are the same in all cases this + last year).
FINANCIALS

Current Financial Info

Fiscal Year Begins: 2017
Fiscal Year Ends: 2017
Projected Revenue: $1,900,000.00
Projected Expenses: $1,900,000.00
Total Projected Revenue includes "in-kind" contributions/donations
Endowment Value: $29,258.00
Spending Policy: Income Only
Spending Policy Percentage: 4

Capital Campaign
In a Capital Campaign: No
Campaign Goal: 0

IRS Form 990s
Extension Letter
Form 990
2014 990
2013 990
2012 990
Form 990
Form 990
Form 990
Form 990
Form 990

Audit/Financial Documents
2015 Audited Financials
2014 Financials
2013 Financials
2012 Audited Financials

Solvency

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<thead>
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<th>Fiscal Year</th>
<th>2015</th>
<th>2014</th>
<th>2013</th>
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<tbody>
<tr>
<td>Current Ratio: Current Assets/Current Liabilities</td>
<td>88.22</td>
<td>73.55</td>
<td>65.05</td>
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Long Term Solvency
### Historical Financial Review

#### Revenue and Expenses

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<th>Fiscal Year</th>
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<th>2014</th>
<th>2013</th>
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<tbody>
<tr>
<td>Total Revenue</td>
<td>$1,835,571</td>
<td>$2,142,519</td>
<td>$1,620,474</td>
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<td>Total Expenses</td>
<td>$1,364,627</td>
<td>$1,541,936</td>
<td>$1,177,755</td>
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#### Revenue Sources

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<th>Fiscal Year</th>
<th>2015</th>
<th>2014</th>
<th>2013</th>
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<tbody>
<tr>
<td>Foundation and Corporation Contributions</td>
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<td>$0</td>
<td>$0</td>
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<tr>
<td>Government Contributions</td>
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<td>Federal</td>
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<tr>
<td>Local</td>
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<tr>
<td>Unspecified</td>
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<tr>
<td>Individual Contributions</td>
<td>$1,672,502</td>
<td>$2,023,745</td>
<td>$1,579,036</td>
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<tr>
<td>Indirect Public Support</td>
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<tr>
<td>Earned Revenue</td>
<td>$158,250</td>
<td>$114,994</td>
<td>$38,962</td>
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<tr>
<td>Investment Income, Net of Losses</td>
<td>$4,819</td>
<td>$3,780</td>
<td>$1,787</td>
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<tr>
<td>Membership Dues</td>
<td>$0</td>
<td>$0</td>
<td>$0</td>
</tr>
<tr>
<td>Special Events</td>
<td>$0</td>
<td>$0</td>
<td>$0</td>
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<tr>
<td>Revenue In-Kind</td>
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<td>$147,411</td>
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<tr>
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<td>$689</td>
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#### Expense Allocation

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<tbody>
<tr>
<td>Program Expense</td>
<td>$1,006,555</td>
<td>$1,133,303</td>
<td>$818,246</td>
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<tr>
<td>Administration Expense</td>
<td>$141,736</td>
<td>$238,503</td>
<td>$192,897</td>
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<tr>
<td>Fundraising Expense</td>
<td>$216,336</td>
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<td>$166,612</td>
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<td>Payments to Affiliates</td>
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<td>$0</td>
<td>$0</td>
</tr>
<tr>
<td>Total Revenue/Total Expenses</td>
<td>1.35</td>
<td>1.39</td>
<td>1.38</td>
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<tr>
<td>Program Expense/Total Expenses</td>
<td>74%</td>
<td>73%</td>
<td>69%</td>
</tr>
<tr>
<td>Fundraising Expense/Contributed Revenue</td>
<td>13%</td>
<td>8%</td>
<td>11%</td>
</tr>
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#### Assets and Liabilities

<table>
<thead>
<tr>
<th>Fiscal Year</th>
<th>2015</th>
<th>2014</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Assets</td>
<td>$2,792,931</td>
<td>$2,332,493</td>
<td>$1,728,344</td>
</tr>
<tr>
<td>Current Assets</td>
<td>$2,718,512</td>
<td>$2,274,435</td>
<td>$1,677,879</td>
</tr>
<tr>
<td>Long-Term Liabilities</td>
<td>$0</td>
<td>$10,396</td>
<td>$11,960</td>
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<tr>
<td>Current Liabilities</td>
<td>$30,815</td>
<td>$30,925</td>
<td>$25,795</td>
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<tr>
<td>Total Net Assets</td>
<td>$2,762,116</td>
<td>$2,291,172</td>
<td>$1,690,589</td>
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#### Top Funding Sources

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<thead>
<tr>
<th>Fiscal Year</th>
<th>2015</th>
<th>2014</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Top Funding Source &amp; Dollar Amount</td>
<td>Contributions, gifts, grants $1,672,502</td>
<td>Contributions, gifts, grants $2,023,745</td>
<td>Contributions, gifts, grants $1,579,036</td>
</tr>
<tr>
<td>Second Highest Funding Source &amp; Dollar Amount</td>
<td>Education Forum $158,250</td>
<td>Education Forum $114,994</td>
<td>Education Forum $39,962</td>
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<tr>
<td>Third Highest Funding Source &amp; Dollar Amount</td>
<td>Investment Income $4,819</td>
<td>Investment Income $3,780</td>
<td>Investment Income $1,787</td>
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</table>
Comments

**Financial Comments by Foundation**
Financial information taken from Federal tax returns. Contributions include corporate and foundation support as they are not separately stated on the tax return.
## PLANS, POLICIES & LICENSES

### Plans
- Fundraising Plan: No
- Communication Plan: No
- Strategic Plan: No
- Management Succession Plan: No
- Continuity of Operations Plan: No

### Policies
- Organizational Policies and Procedures: Under Development
- Written Conflict of Interest Policy: Yes
- Nondiscrimination Policy: Yes
- Whistle Blower Policy: Yes
- Document Destruction Policy: Yes

### Government Licenses
- Is your organization licensed by the Government?

### Planning & Policies Comments
- Planning & Policies Comments by Organization
- Planning & Policies Comments by Foundation