



PULMONARY HYPERTENSION
ASSOCIATION OF CANADA
.....
L'ASSOCIATION D'HYPERTENSION
PULMONAIRE DU CANADA



Annual Report 2014

A Breath Away: PHocus on the Future

Pulmonary Hypertension Association of Canada

Letter from the Chair of the Board



Dear Canadian PH Community,

It has been a landmark year for PHA Canada. Since being founded in 2008, PHA Canada continues to gain structure and to develop even greater expectations for our future! I can proudly say that PHA Canada has clearly become the definitive resource and voice nationally for PH patients, families, healthcare providers, media and government agencies for any and all issues related to PH.

True to our vision of a **better life for all Canadians affected by PH**, the core of our activities remains the support of PH patients and their caregivers and increasing awareness of PH across Canada. In 2014, we completed the 1st ever Canadian survey of the effects of PAH on Canadians, and launched our official Burden of Illness Survey Report through a large-scale media campaign across Canada. We featured an important initiative on CTEPH, which is PH specifically due to blood clots in the lungs, which included a dedicated website and an exciting social media campaign! We have developed the structure of our Early Diagnosis program, which we will continue to grow in 2015. This is a very important initiative, dear to the hearts of many PH patients who may have suffered unacceptable delays in the diagnosis of their PH. Our wonderful PH clinics and therapies can only help Canadian PH patients if they are quickly and accurately diagnosed. Finally, in addition to depending on the tireless efforts of our incredible PHA Canada staff and innumerable volunteers across Canada, we have begun a formal process of engaging 'knowledge

philanthropists'. These skilled people volunteer both their time and considerable expertise in areas such as finance, government relations and fundraising to strengthen PHA Canada's activities. We engaged over 35 knowledge philanthropists this year, and look forward to even more in 2015.

This past year, PHA Canada completed the challenging but vital process of defining our strategic plan for the next 5 years. This will help us to better focus all of our initiatives in order to target the most important issues facing Canadians affected by PH today. A strategic plan also moves PHA Canada forward as a charitable organization, permitting us to apply for accreditation through Imagine Canada, which will open up new avenues for fundraising and support. This work is vital to ensuring PHA Canada remains a stable, strong, effective organization for you well into the future.

We continue to face challenges in dealing with PH in Canada. We are currently dealing with ongoing Government initiatives to restrict access to effective PH therapies because of their significant cost. As well, we recognize the need to work towards securing more stable, diversified funding of PHA Canada's ongoing work. I am confident our new strategic plan will push us forward in our commitment to improve the lives of all Canadians affected by PH. I look forward to getting to meet many of you at the 4th National PHA Canada Conference in Montreal in May 2015!



Sanjay Mehta MDCM, FRCPC, FCCP
Southwest Ontario PH Clinic
London, Ontario

Letter from the National Manager



It has become a running joke at the PHA Canada office that every year when I sit down to write our annual report letter, I always state that "it has been PHA Canada's biggest year yet". This year was no exception. As you read in PHA Canada Board Chair Sanjay Mehta's message, we have made some tremendous strides this year and in the past 6 years. They are strides of which I am incredibly proud, particularly because we have managed to do so with limited human and financial resources.

We have been able to make these strides largely thanks to the sheer will, passion and determination of our PH community. It takes a village to change the face of a disease, and our village is strong: from the dedicated individuals who serve on our board of directors, to our tireless support group leaders, to all of you: members of our PHamily who take it upon yourselves to go out and educate anyone you can. Together, we're changing the face of PH in Canada.

We may not be a huge community compared to some diseases but we are resilient, determined and strong: we are PHighters. Each individual in our community has something unique to contribute

in this PHight: from our smallest warriors to their parents, family members and caregivers; from our newly diagnosed patients to those courageous patients who have lived with PH for 15 and more years, and from our incredibly dedicated doctors and nurses. I am so proud of what, thanks to you, PHA Canada has been able to accomplish in such a short amount of time.

This year we welcomed a group of PHA Canada Ambassadors, who are working on your behalf to raise awareness in their communities and beyond and to advocate on behalf of PHers everywhere. In a few short months, our Ambassadors have already made their mark by achieving over 46 proclamations and holding many meetings with their respective MLAs to discuss the impact of PH. I continue to be amazed by their commitment to our cause, and have no doubt that we will be seeing great things from this spectacular group of people.

In closing, I would like to thank everyone in our community, all of you, who have yet again worked so hard to make this PHA Canada's and the Canadian PH community's 'best year yet'. I look forward to getting to say that again next year.



Angie Knott
National Manager

2014 Highlights

Together, we have achieved so much over the 2014 year. When we look at the highlights over the past year, we can't help but notice that our every success has been due to the dedication and involvement of our members. It's when we all work together that we make the largest impact in creating a better life for all people affected by PH – through advocacy, fundraising and awareness, support and hope. We are truly focusing on the future and cannot wait to see what 2015 has in store. Before January is upon us, we'd like to remember the highlights of the 2014 year.

Knowledge Philanthropy takes off

PHA Canada benefited from the expertise, time and energy of nearly 40 knowledge philanthropists this year. Knowledge philanthropists are expert volunteers: individuals with valuable knowledge who donate that knowledge to PHA Canada by taking on specific projects to help us grow. This year, these generous supporters created nutrition factsheets, translated PH resources into languages like Mandarin and Farsi, edited Conference session audio and much more. We hope to engage even more skilled volunteers in 2015!

Fund for research is launched

Because research in pulmonary hypertension is so important to our community, PHA Canada launched a research fund last spring. This fund is currently collecting donations from member fundraisers across the country. In 2015, we hope to see these funds disbursed towards a specific research project, which will ultimately help Canadian PH patients by allowing young researchers to pursue important PH research.

Paint Canada Purple

In 2014, an initiative from Loretta Chu took hold when members of our community requested that their local monuments be illuminated in periwinkle purple for May 5th, World PH Day. Periwinkle represents the bluish-purple tinge on the lips and fingers of PH patients. On May 5th, we witnessed the Toronto CN Tower, Toronto city hall, Niagara falls, the Fort Erie Peace Bridge and Vancouver's BC Place all illuminated in purple! To paint Canada purple is a fantastic awareness opportunity, and we are excited to expand this campaign in 2015.



Monuments across Canada alight in purple for World PH Day!



Our very first cohort of Ambassadors

Ambassadors

On September 26th, PHA Canada launched our brand new Ambassador Program. Our very first cohort of 10 Ambassadors met in Montreal, QC for a special workshop on their role, which included advocacy and media training. We have ambassadors who are PH patients, parents, caregivers and even a grandparent! Our Ambassadors for the 2014-2016 term are:

- Teri Kingston, caregiver
- Tarya Laviolette, patient
- Stephanie Ricci, parent
- Danush Rudolph, parent
- Caroline Liu, patient
- Kerry Pierce, parent
- Sandy Vachon, patient
- Nicole Dempsey, patient
- Gail Nicholson, nurse
- Don Moores, grandparent
- Ruth Dolan, Board Liaison to Ambassadors

These ambassadors have already been hard at work collecting local Proclamations and telling anyone and everyone about how PH impacts Canadians. We are thrilled about the enormous potential of this program.

...And this isn't all. PHA Canada submitted patient evidence for several new PH medications and for the therapeutic area to the Canadian Agency for Drugs and Technologies in Health this year. Our Lend a Hand for World PH Day collected 6558 handprints, which illustrate the powerful support our community has across Canada. Finally, we created countless new connections, expanding our reach and membership more than ever before. *Together, we are moving towards a bright future.*

Personal journeys

While we are excited about our achievements in advocacy and awareness, the truth is that PHA Canada's most important work is connecting our community. We want for our members and friends to meet one another, because it's in these connections that support is conveyed, common ground is identified, and hope is realized. Our greatest aim is to add value to our members' lives through connecting them with a community, so this year, we wanted to know whether we were achieving that aim. We reached out to both new and old members who have been engaged with our community this year, to find out what being a part of PHA Canada has meant for them. These are Tarya, Don, Caroline and Dianne's stories.

Tarya's story (Vancouver)

I was diagnosed with idiopathic pulmonary arterial hypertension (IPAH) in 2012. At first I didn't really know what was happening – my family doctor explained something about the way the heart and lungs work, and drew a little picture, but I didn't grasp the enormity of it until I went home and googled it. Wow, did things ever change then.

My first instinct was to reach out to other people who had been through the same thing. I'm a big believer in what I call the 'I get it' factor – the value of talking to people who share significant experiences, like a PH diagnosis. I didn't find a local support group, but I got something I didn't expect: I found out that PHA Canada is based right here in my hometown of Vancouver! I went in and had a chat with Angie, and she helped me find ways to connect to the PH community in Canada.

I had to stop working for a while after my diagnosis, so money was tight. Angie encouraged me to apply for a scholarship to attend conference, and I got funded. I can't overstate how important that conference experience was for me. I went into conference feeling fragile, isolated and largely incapable of living out any of my dreams. After three short days of

"It's hard to believe it's been just two years since my diagnosis; my world has turned upside down, and right side up again in such a short time."



"Tarya (rightmost) with Angie and Jas at PHA's 2014 Conference in Indianapolis"

meeting people like me, getting good education on the newest research, and meeting people who were just plain alive more than 10 years after their PH diagnosis was transformative for me.

As I began to get physically and emotionally stronger, I decided to try to return to work. I had just finished a Master's degree in public health, and wanted to put my skills to good use. Luckily for me, PHA Canada had a part-time opening – it couldn't have been a better fit! I was able to use my skills to make a meaningful contribution to my community, and really get to know my fellow PHers at the same time. It was a win-win situation. My time at PHA Canada helped me to gain the strength and confidence

I needed in myself as a professional again to pursue full-time work, when just 18 months earlier, I was convinced I would never work again.

Even though I no longer work on staff at PHA Canada, I remain very connected. I have seen the dedication, the passion, and the love that go into every day's work in that little office, and I continue to be inspired by the staff, board members, and the community at large. It's hard to believe it's been just two years since my diagnosis; my world has turned upside down, and right side up again in such a short time. The right-side up part is thanks to the efforts of PHA Canada and all the PHighters out there, doing what we can to face this together.

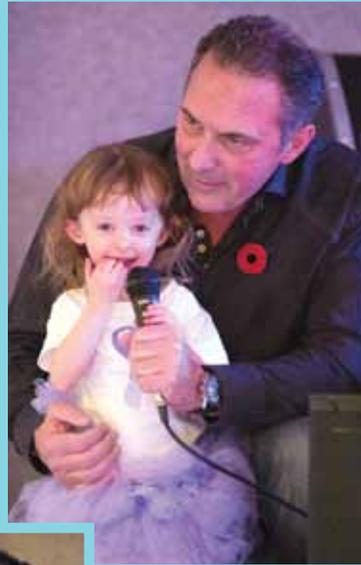
Don's story (Nanaimo)

My granddaughter, Talitha Decker was diagnosed with PH about 18 months ago, when she was 3 years old. When Tally was first diagnosed, my entire family knew nothing about pulmonary hypertension.

It wasn't until we met with Dr. Adatia at the Stollery hospital in Edmonton that we learned about PHA Canada and the amazing support staff and other people involved. Once we became connected to PHA Canada, we found it to be a tremendous resource in helping us learn more about this awful disease. Also, the support from the many people in the association has been overwhelming and greatly appreciated.

Having a community is critical to the well-being of everyone who is affected by a rare disease like pulmonary hypertension. Community acts as much more than a support system: it's also meaningful from a compassion and resource perspective.

The most inspiring part about connecting with others through PHA Canada is witnessing the



"The most inspiring part about connecting with others through PHA Canada is witnessing the courage and determination of patients with PH, big and small."



Don and his wife Sandy in periwinkle for World PH Day!

courage and determination of patients with PH, big and small. There is also the selflessness from caregivers and their unending compassion and drive to bring awareness, education and hope for a cure. The most valuable thing that I've gained from the PHA Canada community is humility. They are a small organization, yet every person is so tireless in their efforts to make a difference, and they really are making life better for those with PH. That to me is so humbling, inspiring and encouraging.



I love the website. There is great information on PH, plus events and news. If I forget something or need updated material, I can always find it there. I love the Facebook page too: the inspiring messages help me cope with everyday living.

PHA Canada's staff are incredible. I really don't know how they do everything they do. PHA Canada has helped me learn so much through conferences, Connections magazine and the pulse. It's helped me to learn so much about others in the PH community through their personal stories. I am so thankful for how much PHA Canada keeps advocating on behalf of patients so that we can have a better quality of life. They have connected so many of us across Canada, and I'm so grateful.

—Jas, PH patient

Caroline's story (Toronto)

I was diagnosed less than one year ago, in January 2014. After being diagnosed, I searched online and read through almost all the information I could get, in English and Mandarin. It was scary at first to know that PH was an incurable disease and if left untreated, my life expectancy would be just two years. I quickly arranged my will for my kids and felt very uncertain about my future.

I learned about PHA Canada through my internet searching. Once I saw there was a patient support group in Toronto, I decided to join both PHA Canada and the support group right away, as I was desperate to know more about the disease and how other patients were dealing with it. I learned a lot more about life with PH from the patients and caregivers in the Toronto support group.

Community is so important when dealing with PH. Patients with such an incurable life threatening disease can feel hopeless, financially

constrained, and isolated. A community with other long term patients can help new patients learn every detail about how to manage the burden of the disease. A community can also be important for caregivers, so that they can get to know other caregivers and exchange feelings. Overall, a community becomes a second family for all people affected by PH. The most inspiring part for me about connecting with others is now being able to provide my knowledge of PH to new patients so that they feel relieved knowing it's possible to continue to live with such a disease.

The most valuable thing I've gained from my connection to PHA Canada

"The most inspiring part for me about connecting with others is now being able to provide my knowledge of PH to new patients so that they feel relieved knowing it's possible to continue to live with such a disease."



is meeting so many amazing people affected by this illness. I've been touched by lives of patients and their caregivers and inspired by how they try to balance everything while dealing with this disease. Their stories encourage me every day to live my life to the fullest.

Dianne's story (Richmond)

I was diagnosed in January 2013 with Chronic Thromboembolic Pulmonary Hypertension (CTEPH), during a hospitalization at Richmond Hospital. Living with CTEPH was very lonely as I tried to deal with the disease's impact on my life. I had always been so active before: now what could I do? It was also challenging to do internet research on PH, as there is a lot of misinformation and the medical community are still learning about this rare disease.

I learned about PHA Canada when I received a booklet from my hospital nurses, which is certainly an excellent start to introduce patients to the challenges and journey of this rare disease. When I contacted Angie at PHA Canada, she connected me with Roberta Massender who is an incredible supporter, and Dianne Gale, who shares my disease. These ladies were truly the most positive introduction to this new world, and I began to see that the importance of community is paramount when dealing with an illness like this. When I was put on oxygen 24/7, talking to people about feeling isolated helped me to see that I wasn't alone. Connecting with others helps us to become educated and aware, and gives us support to get through the tough days. It's also a meaningful outlet to be able to give back.

The best part of being involved with PHA Canada has been meeting special, positive people from all walks of life, and be-



"The best part of being involved with PHA Canada has been meeting special, positive people from all walks of life, and being able to support others."

ing able to support others. I have also had the most caring doctors and nurses who supported me through a very serious surgery and encouraged me to get back on my feet to start a new life again. Finally, connecting with PHA Canada has allowed me to meet friends that have been so caring in looking after me. I feel so blessed.

PHA Canada has shown me that being connected to an association and a community makes going through this challenging journey easier. I have learned how to live a healthy life despite my chronic condition, and this is invaluable. I hope to be able to contribute to our community for many years to come.

Financials

We are pleased to share our financial statements with you. This financial statement reflects a fiscal year spanning only 9 months (April 1st to December 31st 2013) During the 2013 year, PHA Canada's Board made the decision to request a change in fiscal year to a period that runs concurrent with the full calendar year for ease of financial accounting. This request was approved by Canada Revenue Agency, thus creating a shortened fiscal year in 2013. The presented statements were approved by PHA Canada membership on May 31st 2014.

PHA Canada undergoes a yearly financial Review Engagement: please note that this does not constitute a certified financial audit. However, PHA Canada is committed to transparency to our donors and has prepared an internal statement. As of fiscal year 2014, PHA Canada will be undergoing a full financial audit with those financial statements to appear in next year's Annual Report.

REVIEW ENGAGEMENT REPORT

To the Directors Pulmonary Hypertension Association of Canada

We have reviewed the statement of financial position of Pulmonary Hypertension Association of Canada as at December 31, 2013, and the statements of earnings, net assets and cash flows for the period then ended. Our review were made in accordance with Canadian generally accepted standards for review engagements and consisted primarily of inquiry, analytical procedures and discussion related to information supplied to us by the company.

A review does not constitute an audit and consequently we do not express an audit opinion on these financial statements.

Based on our review, nothing has come to our attention that causes us to believe that these financial statements are not, in all material respects, in accordance with Canadian accounting standards for not-for-profit organizations.



Chartered Accountants, Licensed Public Accountants

Windsor, Ontario
May 27, 2014

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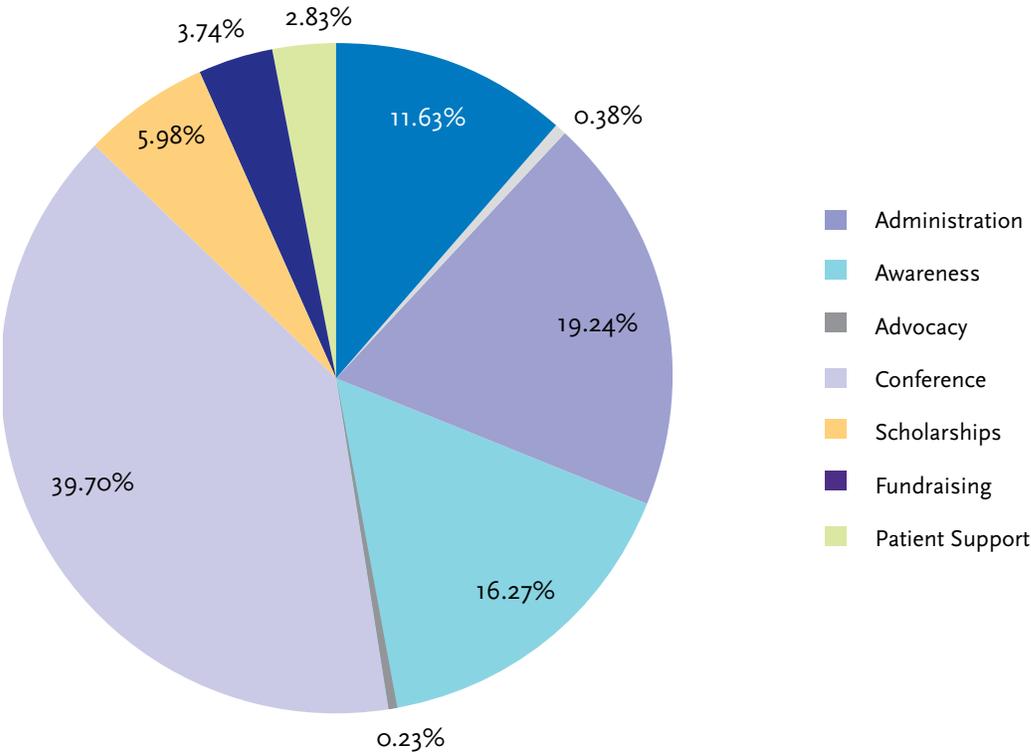
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Financials

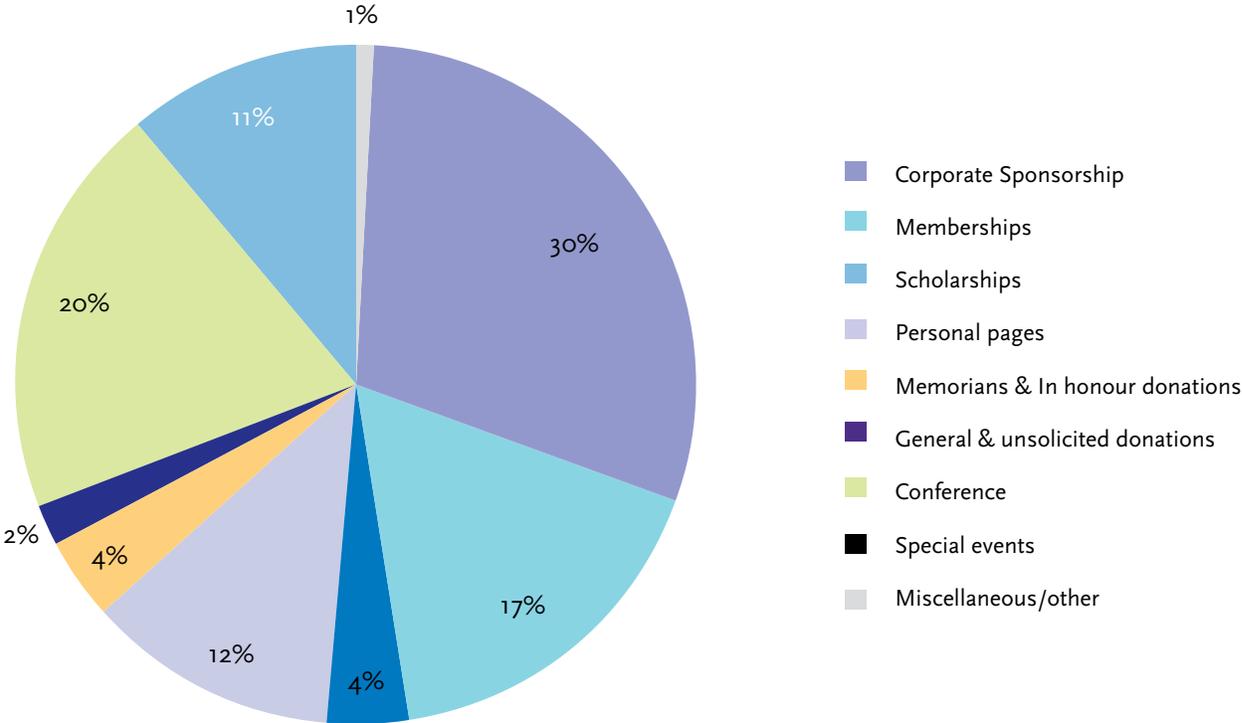
PULMONARY HYPERTENSION ASSOCIATION OF CANADA
STATEMENT OF OPERATIONS AND NET ASSETS
 (UNAUDITED)
 FOR THE 275 DAY PERIOD ENDED DECEMBER 31, 2013

	275 Days Ended December 31, 2013 \$	Year Ended March 31, 2013 \$
REVENUE		
Donations and sponsorships	314,207	343,480
Membership fees	1,865	3,330
Interest	337	801
	<u>316,409</u>	<u>347,611</u>
EXPENSES		
Amortization	1,047	1,476
Awareness and promotion	55,142	25,429
Conference and conference support	136,170	33,764
Insurance	3,324	3,719
Non-refundable portion of GST/HST	6,670	6,564
Office supplies	10,258	16,631
Printing and postage	39,622	35,202
Professional fees	8,884	8,328
Rent	19,880	9,675
Scholarships	18,297	18,000
Telephone	1,538	1,525
Translation services	9,154	6,025
Travel	1,419	21,947
Wages and benefits	89,124	97,352
Website	11,248	8,518
	<u>411,777</u>	<u>294,155</u>
EARNINGS (LOSS) FROM OPERATIONS	(95,368)	53,456
GAIN (LOSS) ON DISPOSAL OF CAPITAL ASSETS		(438)
EXCESS (DEFICIENCY) OF REVENUES OVER EXPENDITURES	(95,368)	53,018
NET ASSETS, BEGINNING OF PERIOD	292,317	239,299
NET ASSETS, END OF PERIOD	<u>196,949</u>	<u>292,317</u>
CASH FLOWS FROM OPERATING ACTIVITIES:		
Excess (deficiency) of revenue over expenditures	(95,368)	53,018
Non-cash items included in the determination of excess (deficiency) of revenues over expenditures:		
Amortization	1,047	1,476
Loss on disposal of capital assets		438
	<u>(94,321)</u>	<u>54,932</u>
Changes in non-cash working capital		
Decrease (increase) in GST/HST recoverable	(13,945)	15,237
Decrease (increase) in prepaid expenses	6,198	(6,198)
Increase (decrease) in accounts payable and accrued liabilities	(7,247)	10,223
	<u>(14,994)</u>	<u>19,262</u>
	<u>(109,315)</u>	<u>74,194</u>
CASH FLOWS FROM INVESTING ACTIVITIES:		
Capital asset acquisitions	(2,103)	(1,900)
Increase (decrease) in temporary investments	(337)	(714)
	<u>(2,440)</u>	<u>(2,614)</u>
NET INCREASE (DECREASE) IN CASH AND CASH EQUIVALENTS	(111,755)	71,580
CASH AND CASH EQUIVALENTS, BEGINNING OF PERIOD	229,212	157,632
CASH AND CASH EQUIVALENTS, END OF PERIOD	<u>117,457</u>	<u>229,212</u>
Cash and cash equivalents comprised of:		
Cash in bank	117,457	229,212

Our expenses



Our revenues



Corporate efforts

The PHA Canada Corporate Committee members support the mission and vision of PHA Canada via a yearly dues contribution.

Corporate Committee members in 2014 were:

Actelion Pharmaceuticals Canada	McKesson Specialty Health	Unither Biotech Inc.
Bayer Inc	Pfizer Canada	
GlaxoSmithKline Inc	Shoppers Drug Mart Specialty Health	

In addition, Corporate Committee members sponsor specific programs, which fit their company mandates. We wish to recognize the dedicated support of our Corporate Committee members and other Corporate partners, who have sponsored us at the following levels beyond their membership contribution:

Platinum

Actelion Pharmaceuticals Canada
Bayer Inc.

Silver

GlaxoSmithKline Inc.
Unither Biotech inc.

We would also like to extend a special thank you to Actelion Pharmaceuticals for going above and beyond in support for the PH Community and for contributing \$5000 in matching funds to PHA Canada's Awareness Month campaign. Thank you Actelion for your continued commitment to the PH community.

The \$5000 in matched funds would not have been possible without the tremendous response and enthusiastic involvement of the PH community in this year's Awareness Month, so thank you to all of you for your great fundraising and awareness efforts.

Our donors

PHA Canada relies on the generosity and dedication of our donors to further our mission and to support our activities. We would like to thank all of those who contributed in any way in 2014. We appreciate each dollar donated, as they make a huge difference in the lives of those living with PH.

We would like to particularly recognize and thank the donors and fundraisers below who either personally contributed sizable amounts or whose fundraising efforts contributed to donations over \$500.

\$500 – \$999

Fuller Utility services
Sirkka Morel

\$1000 – \$2499

Ruth Dolan (fundraising and own contributions)
London Support Group
Sandra Langford
Sanjay Mehta
Bayer Inc.
Menchie's (2288861 Ontario Inc.)
Scotiabank (Cornwall)
Scotiabank (8th St & Clarence Ave)

\$3000-\$4999

Ottawa PH Support Group
Lisa Castle (Sandy Metcalfe Tournament)
John Murray
Glenn Watt

\$5000+

Toronto Chapter
Northern Alberta Chapter
Gail Nicholson (Calgary Masquerade Ball)
Renaë Mohammed (Run for Research)

In 2014, we introduced our new research funding policy*. This policy allows members to contribute towards a fund, which will be allocated helping young researchers interested in pulmonary hypertension research. In 2014, fundraising and donation efforts resulted in the research fund sitting at \$4618.75 at year-end.

*to learn more about PHA Canada's research policy and how you can contribute, please visit www.phacanada.ca/accountability.

Reflection

In loving memory

While our community holds enormous hope for the future, the reality is that pulmonary hypertension still takes loved ones away from us. The success stories from our members, from developments in research and from heightened awareness about PH are worth celebrating, but they cannot bring back the people that we have lost to this disease. The following individuals are those who sadly lost their battle to PH over the 2014 year. Our hearts go out to these individuals and their families.

Ronald Ally	Donald Spitula	Annick Vigneault
Ruth Caroll	Jim Davey	Leon Maurier
Jeannette Doughty	Helen Britt	Claudia Crawley
Geraldine Brown	Helen Scott	Dion Dayanandan
Sophia Sysakis	Micheline Lariviere	Gayle Riley
Robert Flett	Claudia Crawley	

The following individuals passed on during the 2013 year. PHA Canada learned of their passing after our 2013 annual report went to print, and as such, we wish to mention them here.

Yvan Despatis	Regine Theriault
Germain Poulin	Lisa Gress

Looking Forward

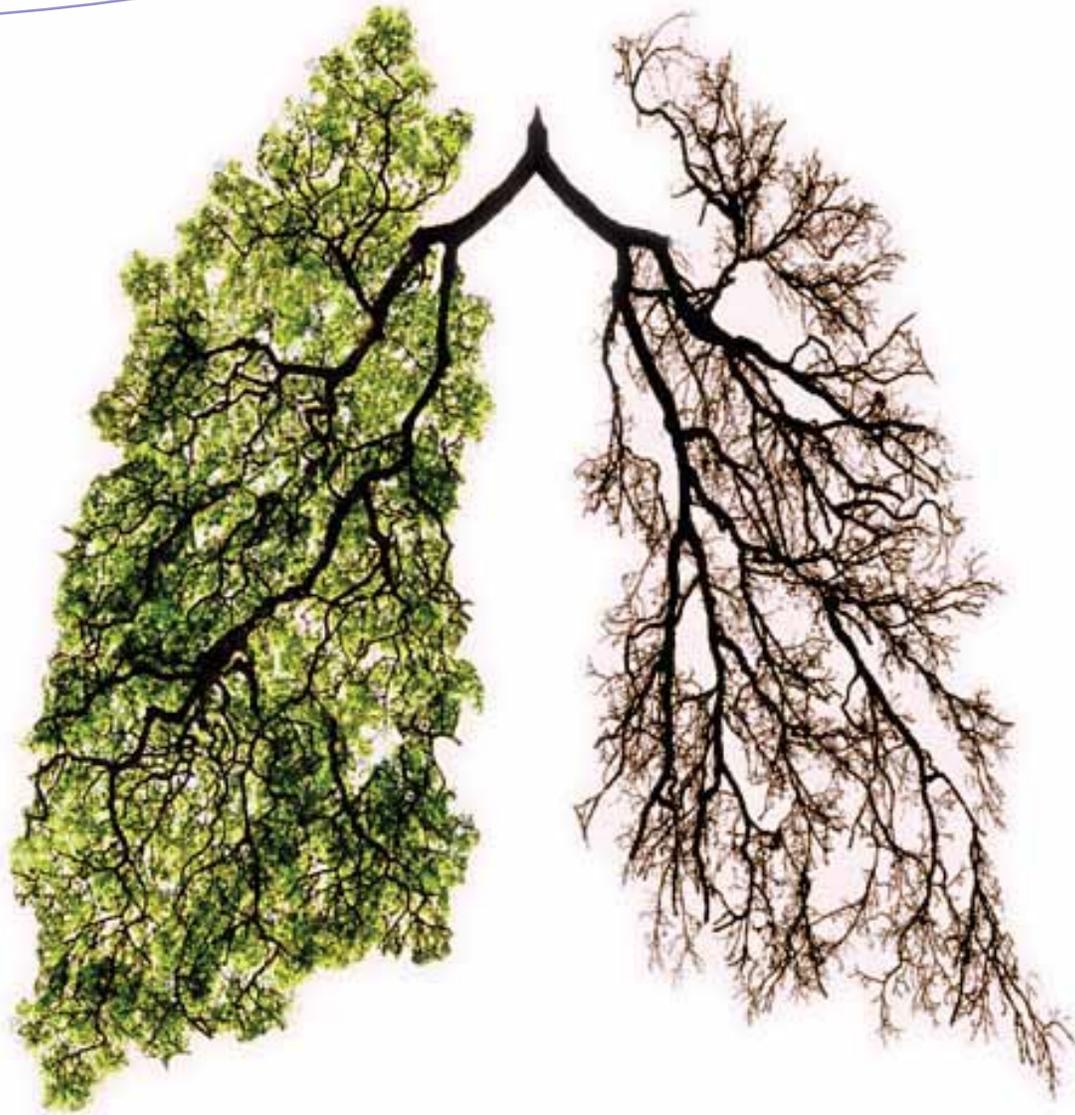
In 2015, PHA Canada looks forward to witnessing far more monuments illuminated in purple for May 5th, World PH Day. We are immeasurably excited about hosting our 4th National PH Conference in Montreal, where we hope to meet PHighters of all ages and learn their stories. We are honoured to share in the lives of those affected by PH across Canada, and are richer because of our strong connections. We believe that 2015 will be a year of hope and promise, and can't wait to see what's in store.





PULMONARY HYPERTENSION
ASSOCIATION OF CANADA

.....
L'ASSOCIATION D'HYPERTENSION
PULMONAIRE DU CANADA



*Dizzy, short of breath
Hypertension of the lungs
Rare, invisible.
-Tarya Laviolette*