

Putting Research FIRST

SHARPER FOCUS.

DEEPER IMPACT.

ACCELERATED PROGRESS.

In 2010 the Association intensified its efforts to build a critical mass of rigorous research that validates the biological basis for CFS and leads to improved methods for diagnosis and treatment. The transformation from a patient support and advocacy organization to one laser-focused on stimulating and supporting research began. Here we share the events of 2010 that highlight our unwavering research focus which we believe will make a deeper impact and rapidly accelerate progress.

January 2010

- **Adam Lesser** became the sixth chairman in the Association's 22-year history to lead the Board of Directors. In "[Passing the Torch](#)," published in the January 2010 *CFIDSLink*, Adam wrote he is honored to hold this position because: "I remind myself that each decision the CFIDS Association makes impacts the lives of everyone with CFS. And that's what keeps me going—the belief that one day we will get there. One day CFS will be diagnosable, treatable, and curable."
- A study testing for evidence of **XMRV infection in CFS patients in the United Kingdom** reported negative results in the January 6 issue of *PLoS ONE*. This was the first publication following the article in the top-ranked journal *Science* from Whittemore Peterson Institute, the National Cancer Institute and Cleveland Clinic that garnered worldwide attention. **Dr. Suzanne Vernon**, Scientific Director of the Association, provided an [analysis](#) of how it compared to the study published in the *Science* paper, and why it heavily underscored the need for more research. The Association also issued a [press release](#) to news outlets across the United States.
- A **series of online webinars** was introduced with **Dr. Lucinda Bateman** explaining XMRV and its significance in the first webinar on January 18. Over 650 people registered for this free resource offered through a generous gift by an anonymous donor. Dr. Bateman, an internist whose practice is dedicated to the management and care of people with CFS and fibromyalgia, covered the basics of research linking XMRV (a human retrovirus) and CFS. She shared some early insights into what this discovery might mean for the field and for patients, as well as her perspective on other current research efforts. Dr. Bateman's archived presentation is available at <http://www.cfids.org/webinar/xmr-v-slides-jan2010.pdf> (PowerPoint slides) and <http://www.cfids.org/webinar/xmr-v-jan2010.mp3> (audio file).



- **Post-exertional malaise** is a cardinal feature of CFS that distinguishes it from many other conditions. A study funded by the CFIDS Association and published in the January 24 issue of [Journal of Women's Health](#) by researchers at **University of Pacific** describes this consequence of modest physical and/or mental activity experienced by most, CFS patients. In "[The Hallmark of CFS](#)", **Suzanne Vernon, PhD**, analyzed the study and provided a description of how exercise challenges that provoke post-exertional malaise are being used by other research groups to further the understanding of CFS.



Dr. Snell, Dr. Stevens and
Dr. VanNess

February 2010

- In response to questions posed on the Association's Facebook page, in online discussion forums and through e-mail, postal mail and calls, the [Association FAQ page](#) was updated.
- One of the Association's advocacy initiatives in 2010 was to [seek inclusion of CFS](#) in the **Department of Defense's Peer Reviewed Medical Research Program**. Throughout the year, the Association asked for stories from current or retired members of the military whose CFS (or CFS-like illnesses) impacted their military service. In the February 2010 issue of *CFIDSLink*, Chief William A. Vernon shared his story, "[Popeye in the Desert.](#)"
- The Association nominated [seven highly qualified individuals](#) for vacancies on the federal **CFS Advisory Committee** (CFSAC).
- In the second of the Association's series of online **webinars**, **Dr. Suzanne Vernon** provided an [overview of the Association's research program](#) and the six innovative studies funded through generous donors on February 18. **
- The CFIDS Association's **Facebook** page marked its first anniversary on February 28, providing 3,445 fans with regular updates, a lively forum for the exchange of support, ideas and debate. New information is posted daily and often more frequently.

March 2010

- The Association announced the creation of the [SolveCFS BioBank](#) which will collect and store a bank of biological samples (such as blood, tissue, cells and DNA) and clinical information from CFS patients and healthy individuals. Samples will be available to researchers whose research projects have been reviewed and approved by the CFIDS Association of America Medical Research Advisory Committee. Approved-researchers are required to publish their results in peer-reviewed medical journals. Since securing approval for the **SolveCFS BioBank**, the Association has established its first study collaboration and opportunities to work with several clinical and academic collaborators and major industry partners.



- Members of the [Association's Board of Directors and staff](#) met with **Congressional appropriators** on March 3 and 4 to advocate for the expansion of CFS research funding by the Department of Health and Human Services and the Department of Defense.



- On March 22, **Dr. Marvin Medow** joined participants for a [webinar](#) on his group's research into **orthostatic intolerance in CFS**. Dr. Medow described his study of abnormal blood flow in patients with CFS and Orthostatic Intolerance and the techniques his team uses to measure blood flow and chemical changes that may explain many of the symptoms experienced by CFS patients. Participants learned about orthostatic intolerance, tilt table testing, transcranial Doppler and microdialysis. **

April 2010

- To help answer questions received most often about the **SolveCFS BioBank**, the Association published a ["Frequently Asked Questions"](#) document. Recruitment for the **SolveCFS BioBank** had a tremendous start in its first month: 102 patients meeting enrollment criteria were sent materials; 41 blood and tissue collection kits were shipped and 13 completed clinical questionnaires were returned.
- In the April issue of *CFIDSLink*, a new periodic feature was introduced, a **guest editorial** on a research topic of high interest to readers. **Kurt Rowley, PhD**, independent researcher and writer, shared his view about the formal and informal process of achieving consensus in his essay, ["Is XMRV a New Paradigm for CFS? The Role of the Scientific Consensus Process in the XMRV Debate."](#) In his conclusion, Dr. Rowley states "...In my opinion, simply setting the goal of achieving a scientific consensus could foster significant change, helping researchers focus on an eventual paradigm shift for CFS. Even a preliminary consensus on a new research topic might foster change, raising awareness of the need for better social response to CFS patients, better government policies, more insurance coverage for CFS, and validated medical treatment options for patients..."
- The Association sought input from outside experts regarding the creation of a new category called "Complex Somatic Symptoms Disorder" (CSSD) in the revised **Diagnostic and Statistical Manual for Mental Disorders**. On April 1, the Association submitted its [comments on the DSM-5 proposal](#) with an urgent recommendation to abandon creation of the CSSD classification.
- The April 4 issue of the [Wall Street Journal](#) reported on the interagency federal efforts to assess the potential risks to the blood supply posed by XMRV. The article mentions the task forces working on this important issue on which Association President and CEO **Kim McCleary** and **Suzanne Vernon, PhD** serve, as well as the Association's **SolveCFS BioBank**.



- In a [webinar](#) on April 14 **Dr. Leonard Jason** provided an explanation of the various **definitions and diagnostic criteria for CFS**, how they impact research and care, and how the definitions might be improved to better serve researchers, clinicians, and patients. Dr. Jason explored whether the current CFS and ME/CFS case definitions adequately identify patients who have this illness. He has been engaged in several of the efforts to craft meaningful definitions for CFS which could facilitate the identification of biological markers for this illness. **

May 2010

- The Association's **6th Annual Virtual Lobby Day** provided four easy-to-use letter templates reinforcing the CFSAC's recommendations, requesting expanded research from Congress, President Obama and VP Biden, urging members of Congress to attend the May 19 briefing on chronic pain in women, and requesting media coverage from local broadcast and print media outlets.

- The spring 2010 issue of [The Pain Practitioner](#), published by the American Academy of Pain Management, featured an article about CFS by **Kim McCleary** and **Suzanne Vernon, PhD**. This journal reaches 6,000 professionals who manage pain patients.



- **Julia Newton's** group at University of Newcastle published results of a study showing **muscle proton abnormalities** following exercise in CFS patients the *Journal of Internal Medicine*. **Suzanne Vernon, PhD**, described this study and how it brings together other pieces of the CFS puzzle in the "[Litmus Test.](#)"
- In conjunction with the National Institutes of Health, Virology Education began organizing the [1st International Workshop on XMRV](#) for September 2010. **Dr. Suzanne Vernon** served as a member of the Scientific Committee and a session chair.

- On May 4, in Part II of the mini [webinar series](#) about the Association's research program, **Dr. Vernon** described the funded research projects of **Gordon Broderick, PhD**, University of Alberta, **Sanjay Shukla, PhD**, and **Bud Mishra, PhD**. **
- Organization leaders described four of the conditions that have sidelined as many as 50 million lives and cost up to \$80 billion each year in the May 5 [webinar](#). The four conditions spotlighted were: **chronic fatigue syndrome, endometriosis, temporomandibular (TMJ) disorders** and **vulvodynia**. **

- The federal **CFS Advisory Committee** met on May 10. Minutes of the meeting and copies of presentations were posted to the official [CFSAC website](#). Several of the recommendations for the committee's charter were adopted from the Association's testimony provided by [Kim McCleary](#).



- **Suzanne Vernon, PhD**, represented the Association at the **International Society for Biological and Environmental Repositories (ISBER)** 2010 Annual Meeting, "Diversity in Biobanking: Embracing Differences, Harnessing Commonalities," May 11-15, in Rotterdam.
- The CFIDS Association, along with three other organizations and the Congressional Caucus on Women's Issues, launched the [Campaign to End Chronic Pain in Women](#) on May 19. This Campaign **aims to improve the quality of life for all those living in pain** by raising awareness of chronic pain conditions that disproportionately impact women, as well as the neglect, dismissal and discrimination faced by women suffering from chronic pain. Men suffering the double stigma of chronic pain and conditions commonly considered to be women's conditions were addressed as well in this campaign.



- **Dr. Charles Lapp** of the Hunter-Hopkins Center in Charlotte, NC, was the guest speaker for the [webinar](#) held on May 20, describing his "**Stepwise Approach to Treating CFS & Fibromyalgia.**" The Stepwise Approach uses traditional medical therapy complemented by proven wellness techniques to restore well-being and help the sufferer to improve naturally. This is accomplished through education, proper nutrition, low level graded activity, medical management of symptoms, control of perpetuating factors and supportive therapies. **

June 2010

- A **Risk Factors Survey** was launched on the Association's web site with 1,750 people responding. Risk factors refer to traits, events, environments, exposures, etc. that may be more common among people with a certain condition than those who don't have it. Risk factors are not the same as causes. Many of the survey questions came from the National Health and Nutrition Examination Survey which allows for the comparison of answers to the same question from a broader population.
- **Dr. Gordon Broderick**, one of six researchers funded by the Association, and colleagues from University of Miami and the Association, published a study in [Brain, Behavior and Immunity](#) titled, "A formal analysis of cytokine networks in CFS."
- The **SolveCFS BioBank** began inviting patients with a physician's diagnosis of CFS, post-exertional malaise and cognitive difficulties to enroll for future studies under new criteria for [General Enrollment](#). Under General Enrollment, participants provide written informed consent and complete detailed clinical questionnaires to become part of future SolveCFS BioBank studies. This new enrollment status facilitates greater participation by members of the community and expands the clinical population available to interested investigators.
- The spring/summer 2010 issue of [SolveCFS: The Chronicle of the CFIDS Association](#) was mailed to all donors of \$35 or more. Featured stories include updates on XMRV, the SolveCFS BioBank, public policy efforts and Association webinars.



- **Suzanne D. Vernon, PhD**, and **Liz Horn, PhD, MBI**, director of the Genetic Alliance BioBank presented information on the progress of the **SolveCFS BioBank** in a [webinar](#) on June 8 and discussed the ways in which this biorepository enables patients to participate directly in cutting-edge research. **
- **Dr. Vernon** took an in-depth look at three of the Association's funded research projects during the June 17 [webinar](#). Projects discussed included **Dr. Kathy Light** of the University of Utah, **Dr. Dikoma Shungu**, of Weill Medical College, Cornell University and **Dr. Marvin Medow**, associate professor at New York Medical College. **
- On June 18, the **AABB** (formerly the American Association of Blood Banking) issued a [bulletin](#) to its membership advising that CFS patients be discouraged from donating blood. The bulletin included information about CFS and a poster for use in blood donation centers. The CFIDS Association issued a [statement](#) commending AABB's action.
- **24 Hours in the Enchanted Forest: A Race to SolveCFS**, a mountain bike endurance event, was held on June 19-20 near Gallup, New Mexico. It was planned by volunteers who support the CFIDS Association of America and attracted mountain bikers and other sports enthusiasts to the cause. As the first grassroots fundraising event in the 24 year history of the Association, the event raised well over \$25,000 for CFS research.
- **Kim McCleary** represented the Association at the **National Partnership for Women & Families** annual luncheon in Washington, D.C. on June 24. Secretary of Health Kathleen Sebelius was the keynote speaker and 2010 honoree at this event that attracted more than 1,000 guests from government, industry, healthcare and the nonprofit sectors. At the event she hand-delivered material about CFS to the Secretary and to other agency and nonprofit leaders.
- **Suzanne D. Vernon, PhD**, gave a presentation about the current status of CFS research at the **6th Conference of Fatigue Science** in Osaka, Japan, June 24-26. The large, well-orchestrated group of CFS researchers and clinicians is making impressive progress toward objective diagnostics and treatments.

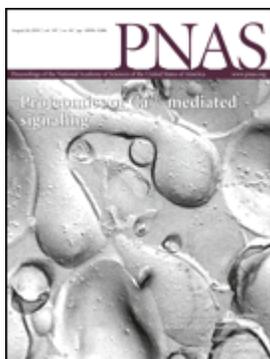


July 2010

- The CFS pages of the **CDC's web site** were updated in late July and drew negative attention and deep concern about the information presented to the public and the health care community. The CFIDS Association and other organizations contacted several CDC staff in an effort to reshape the site to reflect a broader knowledge base and greater accuracy.
- **Kim McCleary** was a speaker at the [2010 Genetic Alliance Annual Conference](#), "Advancing Novel Partnerships," July 15-18, in Bethesda, Maryland.
- Columbia University virology professor and host of the popular podcast "This Week in Virology," **Vincent Racaniello, PhD**, and **Lucinda Bateman, MD**, teamed up for a [webinar](#) on July 15 providing an **update on what is known about XMRV**, its association with human disease and how research should move forward to understand its role in CFS. **

August 2010

- **Dr. Dikoma Shungu** and colleagues at Weill Cornell Medical College with funding from the Association, published a study in [NMR in Biomedicine](#), documenting increased **lactate levels in the cerebral spinal fluid** that correlate with the severity of mental fatigue specific to CFS subjects tested. This group tested some of the same CFS subjects as **Dr. Marvin Medow** at New York Medical College and will compare data to elucidate patterns that might explain these results as well as elucidate other correlations between observations of the central nervous system and autonomic nervous system.
- Transfusion medicine and infectious diseases specialist **Louis M. Katz, MD**, presented a [webinar](#) on **Blood Safety & XMRV** on August 12. Providing background about blood safety issues related to xenotropic murine leukemia virus-related virus (XMRV), Dr. Katz reviewed current XMRV research initiatives and discussed investigations of the retrovirus by those working in transfusion medicine. **
- **Securing disability benefits** from your employer or the government is one of the most common legal issues faced by people with CFS. In a [webinar](#) on August 19, disability attorney **Charles "Mac" Sasser** covered the different types of disability benefits, reviewed the SSA's CFS ruling, and described how to navigate the process of obtaining benefits. **
- Results of a **highly anticipated study** of XMRV in CFS patients conducted by researchers at the



FDA and NIH was published in the [Proceedings of the National Academy of Sciences](#) (*PNAS*) on August 23, and generated worldwide media coverage by print, broadcast and online news outlets.

In the days following publication of the *PNAS* article, the Association collected [frequently asked questions](#) about the study and media coverage it generated. Answers were requested from a range of experts familiar with this study, the emerging field of research into XMRV and other murine leukemia retroviruses, blood safety issues and the related media coverage. Questions were answered by Drs. Shyh-Ching Lo, Harvey Alter, Anthony Komaroff, Judy Mikovits, Louis Katz, Robert Silverman and other experts.

With all the attention focused on CFS and its association with a family of murine leukemia viruses, **what studies should come next?** **Suzanne Vernon, PhD**, provided [her perspective](#) on this question and how the latest discoveries can help advance diagnosis and treatment for CFS.

September 2010

- With continued coverage of XMRV, the Association updated its [comparison of published studies](#) and [XMRV Resources](#) page to reflect the latest studies.
- **Dr. Peter Rowe** was the first person to establish a substantial overlap between **OI and CFS** (although not everyone with OI suffers from CFS, and not everyone with CFS experiences OI). Dr. Rowe shared an informative [webinar](#) presentation on September 1 that detailed the various forms of OI, explored the condition's relationship to CFS and offered tips and tricks to manage Orthostatic Intolerance. **



- The [First International XMRV Workshop](#) was held at the National Institutes of Health on September 7-8. The meeting brought together researchers working on a wide range of studies and the program featured sessions on CFS and prostate cancer. **Suzanne Vernon, PhD**, and **Kim McCleary** represented the Association at this important conference. The closing session Q&A was webcast to the public.
- On September 16, **Dr. Anthony Komaroff**, a long-time CFS clinical researcher and a collaborator on the latest study of murine leukemia viruses addressed **CFS & the Viral Connection** in a [webinar](#). Dr. Komaroff described infectious agents that have been associated with CFS over time, including XMRV and MLVs. **

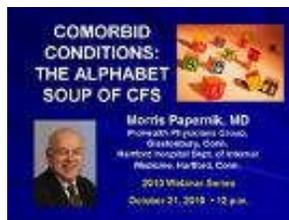
October 2010

- The Department of Health and Human Services (DHHS) solicited nominations for five appointed positions on the **CFS Advisory Committee** (CFSAC) that will come open in April 2011. The CFIDS Association nominated [seven highly qualified individuals](#) to be considered. The selection process is handled by DHHS in accordance with the Federal Advisory Committee Act.
- **Expanding sources of research funding** is central to the CFIDS Association's mission and is its core strategy. For the first time, the U.S. Senate Appropriations Committee for the Department of Defense included CFS as an eligible topic for the \$50 million **Congressionally Directed Medical Research Program** for fiscal year 2011. The Association was [instrumental in justifying the relevance of CFS](#) to military and civilian health, a requirement to be deemed eligible for funding.
- The [Association's summary](#) of the 1st International XMRV Workshop was recognized by the popular podcast "[This Week in Virology](#)" as a **Weekly Science Pick**.
- Three of the six research teams funded by the CFIDS Association shared preliminary data from their projects, as well as other outcomes of Association support, during an October 5 [webinar](#), "**Expanding Research: Building on Your Investment.**" Participants were excited to hear about data sharing that's "connecting the dots" and about new funding awards and clues to target treatment. **
- The DHHS [CFS Advisory Committee](#) met on October 12-14 in Washington, D.C. The meeting agenda was set by DHHS in consultation with members of the CFSAC. The first day of the meeting was dedicated to the science of CFS and featured presentations from NIH-funded investigators and others about a variety of topics, including XMRV. Day two focused on issues related to documenting vocational disability and other employment-related issues that fall under the recently renewed CFSAC charter. On day three, the committee heard federal



agency presentations and subcommittee reports, as well as made recommendations to the Secretary of Health.

Representing the Association, [Kim McCleary](#) urged the committee to develop a comprehensive research agenda for the Department of Health and Human Services to serve as a blueprint for health agencies, academia, industry and nonprofits to meet the challenges of CFS head-on.



- Internist **Dr. Morris Papernik** addressed conditions that frequently co-exist with CFS in the October 21 [webinar](#), "**Comorbid Conditions: The Alphabet Soup of CFS.**" Comorbid conditions are those illnesses or disorders that are present in addition to a primary disease or disorder. Dr. Papernik shared information about the most common comorbid conditions found in CFS patients, together with tips for dealing with multiple disorders. **

November 2010

- Better Business Bureau's **Wise Giving Alliance** conducted its [biannual evaluation](#) of the CFIDS Association of America according to its 20 Standards of Accountability for Charitable Organizations and reported that the Association remains fully compliant. The Wise Giving Alliance standards seek to encourage fair and honest solicitation practices, to promote ethical conduct by charitable organizations and to advance support of philanthropy. The CFIDS Association is the only CFS-focused organization to have received this designation from the Wise Giving Alliance.
- The [fall 2010](#) issue of ***SolveCFS: The Chronicle of the CFIDS Association*** was mailed to all donors of \$35 or more. A message from the Association's Board of Directors titled "[Not One Alone](#)" was featured in response to the extraordinary events occurring in CFS research. In their message, the board stated

"...CFS will not be solved by one person or one organization alone... We need a diversity of strategies and tactics. We need a chorus of voices and opinions. We need coordination of effort, sharing of expertise and collaboration on a level greater than the CFS community has ever attempted.

At this critical time in CFS history, the CFIDS Association stands with you, firm in our resolve to stimulate research aimed at the early detection, objective diagnosis and effective treatment of CFS through expanded public, private, and commercial investment. None of us is in this fight alone."

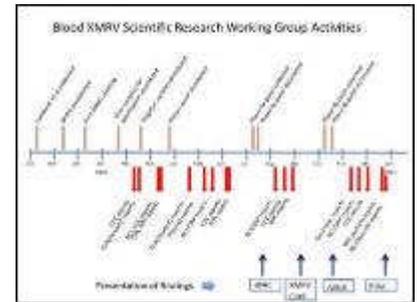
- The Association launched its **annual fund campaign** to provide the financial support for programs that will stimulate research aimed at the early detection, objective diagnosis and effective treatment of CFS through expanded public, private, and commercial investment.
- **Dr. Lucinda Bateman** shared strategies about how to enhance communication with your medical team and avoid leaving the doctor's office feeling frustrated and depressed in the November 11 [webinar](#) titled "**Doc Talk: Communicating With Your Health Care Professional.**" **



- Also featured in November were **Bruce Campbell, PhD** and **Dane Cook, PhD**, experts in the areas of pacing and exercise physiology. In the November 18 [webinar](#), "**Minimizing Relapses: Pacing Yourself Through the Holiday**," they discussed the science behind post-exertional relapse and how to avoid relapse during the holiday season. **

December 2010

- The December 2 [webinar](#) "**Spirituality and Health**" featured **Dr. Gail Ironson** with a review of the current scientific findings on spirituality, religion and health, shared ways in which spirituality can help one cope with chronic illness and provided a guided imagery exercise that participants called "a gift." **
- **Newsweek**, the world's second-largest news weekly magazine, provided readers of the magazine and online content with an [update on CFS](#) and viral research that has been the focus for the past year in the December 6 print edition. Twenty years ago, CFS was *Newsweek's* cover story for its November 12, 1990 edition.
- The FDA's **Blood Products Advisory Committee (BPAC)** heard nine presentations about XMRV/MLVs at its December 14-15 meeting, including interim results of the Blood XMRV Scientific Research Working Group's study. BPAC members voted 9-4 in favor of FDA asking donors about a medical history and/or diagnosis of CFS as a basis for indefinite deferral.
- **Drs. Graham Simmons, Michael Busch and Steven Kleinman** participated in a [webinar](#) on December 17 providing an update on the **Blood XMRV Scientific Research Working Group's** activities, including interim results of Phase II of the four-phase study. **



** Video recordings and slide presentations of all 2010 webinars are available on the Association's [website](#) and [YouTube channel](#).

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THE CFIDS ASSOCIATION OF AMERICA, INC.

Statement of Activities
 Year Ended December 31, 2010
 (With Comparative Totals for Year Ended December 31, 2009)

	Year Ended December 31, 2010			Totals	Year Ended December 31, 2009
	Unrestricted	Temporarily Restricted	Permanently Restricted		
Support and revenues					
Public support:					
Contributions and grants	\$ 962,740	\$ 139,405	\$ -	\$ 1,102,145	\$ 859,859
Federal funds:					
Government grants	142,428	-	-	142,428	228,380
Revenues:					
Membership dues	-	-	-	-	62,172
Pharmaceutical contracts	77,855	-	-	77,855	-
Educational material sales	2,404	-	-	2,404	5,246
Change in beneficial interest	-	1,375	-	1,375	2,033
Interest and other	1,678	-	-	1,678	3,901
	<u>81,937</u>	<u>1,375</u>	<u>-</u>	<u>83,312</u>	<u>73,352</u>
Net assets released from restrictions	429,543	(429,543)	-	-	-
Total support and revenues	<u>1,616,648</u>	<u>(288,763)</u>	<u>-</u>	<u>1,327,885</u>	<u>1,161,591</u>
Expenses					
Program services:					
Research	940,419	-	-	940,419	727,778
Public Policy	253,585	-	-	253,585	197,781
Education	158,349	-	-	158,349	447,470
Supporting services:					
Management and general	72,916	-	-	72,916	108,827
Fund raising and development	148,904	-	-	148,904	119,029
Total expenses	<u>1,574,173</u>	<u>-</u>	<u>-</u>	<u>1,574,173</u>	<u>1,600,885</u>
Change in net assets	42,475	(288,763)	-	(246,288)	(439,294)
Net assets					
Beginning of year	824,038	398,875	5,400	1,228,313	1,667,607
End of year	<u>\$ 866,513</u>	<u>\$ 110,112</u>	<u>\$ 5,400</u>	<u>\$ 982,025</u>	<u>\$ 1,228,313</u>