

FALL 2019

DYS/COURSE

NEWS OF FAMILIAL DYSAUTONOMIA (FD)

**FD FAMILIES CAN HELP
ADVANCE RESEARCH**

**COLLABORATION
HELPS FD CENTER
GAIN INTERNATIONAL
RECOGNITION**

**DYSAUTONOMIA
CENTER WELCOMES NEW
NURSE PRACTITIONERS**



**FAMILIAL
DYSAUTONOMIA**
FOUNDATION, INC

PIP



Family photo from the 1950's featuring Ruth Halle (top right) and Linda Halle (bottom left) with David Halle, age 4 (bottom center).

Renewed Connections

While attending NORD's RARE Summit in Washington DC, FD Foundation VP **Laurent Landau**, his wife **Robin** (parents of Sam), **Dr. Lucy Norcliffe-Kaufmann** and **Lanie Etkind**, Executive Director, had the rare opportunity to reconnect with a former FD Family. **Ruth Halle**, her daughter **Linda Halle** and Linda's husband, **Richard Bopp**, stopped by the hotel one afternoon. Mrs. Halle brought along a vintage photo of her family, including her son David, who lost his battle with FD at age 5 ½. Dr. Norcliffe-Kaufmann was fascinated to learn from Mrs. Halle about how David was diagnosed in the 1950's, and about the family meeting Dr. Riley, who first recognized the disorder (FD was formerly known as Riley-Day Syndrome). The group was especially honored to wish Mrs. Halle a happy 92nd birthday!



FD Foundation Executive Director Lanie Etkind looks at family photo with Ruth Halle and Linda Halle



L to R: Kaia Dalamo and Zenith Kahn

NYU Dysautonomia Center Welcomes Two New Nurse Practitioners

Meet **Kaia Dalamo**, who joined the NYU Dysautonomia Center in October. Kaia has been in the health care field since she was 18-years-old. She began her career as a certified nursing assistant, received her B.S. in Nursing from Northern State Arizona University, followed by her Doctor of Nursing Practice from the University of Arizona. Upon graduation, she spent seven years in an acute care teaching hospital in Tucson while also teaching a semester of nursing at her alma mater. According to Kaia, "I had worked with patients with other dysautonomia disorders before and am now honored to care for patients with FD. It's particularly exciting to me to be a primary care provider within this specialized population."

Zenith Khan joined the NYU Dysautonomia Center team in August. Zenith became interested in nursing through her love of Disney. "I've probably been to Disneyland 150 times," says the California native. "When I was 13, I had an accident while I was there and broke my hand, but I still went on the rides! I had no health insurance and at the ER, I saw how the nurses helped people despite their socioeconomic status and that really resonated with me." In high school, Zenith took classes to become an LPN and then attended UCLA to become an RN. After graduation, Zenith went to Mexico to start a free clinic. "I was astounded at the resiliency of the people there and saw how we could profoundly change an outcome for someone," she said. In Mexico, Zenith started a health education program and a pharmacy and fully immersed herself in the community. "This really brought out my empathy and that's why I went into pediatrics," adds Zenith. She later worked as an RN at the Children's Hospital in Los Angeles with renal, liver and transplant patients before moving with her husband, who is in Emergency Medicine, to Brooklyn. Asked what she is most excited about in joining the Center, Zenith responded, "I want to develop a partnership with the parents, FD patients and the entire care team and form an alliance so I can give the best care to each person."



Jack Posnack plays guitar at Camp Simcha.

“Jack Attack” Gives Back

Robin Fiddle Posnack of New City, NY, has poured her heart and soul into providing her son **Jack**, who has FD, not only with physical care but also with socialization. Every summer since he was 6, Jack has spent two weeks at Camp Simcha, a sleepaway camp run by Chai Lifeline, that provides services for Jewish children with life-threatening and chronic illnesses. Counselors there lovingly nicknamed the little boy “Jack Attack,” and made him a member of the camp band, where he plays guitar. Ms. Posnack always sends her son to camp with a pile of Jack Attack T-shirts printed in different colors. She still chokes up when she recalls how one counselor called to tell them he was wearing his Jack Attack T-shirt on a visit to Jerusalem’s Western Wall.

While Jack has camp friends, it’s more difficult for him during the school year. Yet his social circle widened exponentially about three years ago, when he started playing online games; his favorites now are Fortnite and Madden NFL. Gaming turned out to be an effective vehicle for leveling the playing field and enabling Jack to forge friendships near and far.

“Every Sunday, local kids he’s met in the virtual world come over to have game night with him,” Ms. Posnack reported. “That includes groups from the Jewish Community Center, Boy Scouts, football and tennis players; people of all ages, colors, and orientations. We had an autistic girl come over, and her mother was crying, because this child has never been part of any group before.”

As part of the celebration of his bar mitzvah in January, Jack decided to raise money to give a gaming system to a child with disabilities who was suffering from social exclusion. He created a contest and asked children to email him their stories so that he could pick a winner. Ms. Posnack co-founded a nonprofit organization, soon to get 501(c)(3) tax-exempt status, in order to accept donations and sponsorships to help Jack with his mission. They hope to raise enough money to buy gaming systems for additional winners as well.

Adds Ms. Posnack, “Because of online gaming, Jack is having a ball and he’s connecting with people. Jack Attack doesn’t take one second for granted, and he is living proof that having friends makes a difference and gives life a special purpose.”

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NEXTGEN: Looking to the NextGen(eration)

With the leadership of founder **Adam Kietz**, older brother of **Josh Kietz**, NextGen has taken off. An initiative supported by siblings and cousins of people with FD, the NextGen group is excited to be making an impact in the FD community through social events and fundraising.

So far this year, the junior board has successfully hosted their annual Spring fundraiser Spinning for FD, mingled at a summer happy hour, and met for a board meeting. In the works is an outing with NextGen members and their relatives with FD, a holiday party, and a happy hour fundraiser, as well as even more spinning in 2020!

Interested in getting involved and helping your sibling, cousin or friend with FD? Email Natasha at nweinstein@famdys.org.

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Message from the Executive Director

It takes a village...

I know it may be a cliché, but in the case of FD, this adage holds true. In our small—but

mighty—FD community, many people come together to advance our mission. And because we are not a large group, even the smallest of gestures can generate a significant impact.

As you will read in this issue, there are people who created fundraisers for FD, including **Mike Zucker**, who rode his bike across Iowa in RAGBRAI in honor of his daughter **Sarah Zucker**, and **Ryan Lane**, who raised more than \$20,000 for FD in honor of his friend **Perry Goldberger** when he ran the New York Marathon this November.

There are brilliant **scientists**, who have dedicated years of their lives to unraveling the mysteries of FD and ensuring better and longer lives for those affected (read more about the FD Research Consortium on page 9).

We are fortunate to have wonderful volunteers, like **Perry Goldberger**, who helps out in the office several times a week, and **Rachael Eisenson**, who lends her graphic design talent.

We have benefited from the posthumous generosity of many parents, grandparents, aunts, uncles and friends who included the FD Foundation in their estate plans. The Foundation is now launching the **Forever Devoted** society to acknowledge past and future planned gift donors. Please contact us for more information.

We are fortunate that our **NextGen** group of siblings, relatives and friends of people with FD is building steam, planning fundraisers and social events. (The group is still accepting members, so please contact us if you're interested.)

And finally, our annual crowdfunding campaign, **#FDMATCH19**, still underway at press time, brings together more than 20 fundraisers who each created their own mini-campaigns, reaching out to their personal networks on behalf of a loved one with FD.

No matter what your talent, interest or ability there are many ways YOU can get involved, further our mission, and make a difference to enhance the lives of all those affected by FD. We'd love to hear from YOU!

With heartfelt appreciation,

Lanie Etkind

Are You *Forever?* DEVOTED?

Meet Bea Klier

Bea, age 102, is a former scientist and a published author, now working on her third book. Her son Peter, a math whiz, passed away from FD in the 1970's, when the disorder was still called Riley-Day Syndrome.

To honor her son Peter's memory, Bea has made provisions in her will for the FD Foundation to receive a portion of her estate.

"The FD Foundation was there for me and my family when we needed them, and I have decided to leave a bequest to the Foundation to honor my son Peter's memory, and ensure that the Foundation will be there for other families today and in the future."

We are honored to include Bea Klier as a founding member of Forever Devoted, the FD Foundation's planned giving recognition society and we'd like to add your name too.

There are many ways to include the FD Foundation in your estate plans, such as:

- Leave a bequest to the Foundation in your will or living trust.
- Name the Foundation as a beneficiary of your IRA, 401K, or annuity.
- Name the Foundation as a beneficiary of an investment or bank account.
- Name the Foundation as a beneficiary of a life insurance policy.

If you've already included the Foundation in your estate plans, please let us know so we can acknowledge you as a founding member of Forever Devoted.

For more information, contact Lanie Etkind, Executive Director, at letkind@famdys.org or 212-279-1066.





President's Message

Celebrating the Jewish New Year and reflecting on our own shortcomings and aspirations during the high holy days reminds us of the need for renewal in our efforts to "repair the world." This newsletter is filled with wonderful examples of how this is happening in the FD universe. We take heart from the efforts of so many people who are continuing to find new ways to build our community, establish opportunities of all sorts for our loved ones, raise money to support our outstanding medical care at the Dysautonomia Treatment Center, and generate exciting new scientific research among the extraordinary scientists who are working on the cutting-edge of their fields, exploring everything from possible gene therapies to new treatments for crisis, and more that will benefit those living with FD.

Our supporters span almost a century, from Jack Posnack – who just celebrated his Bar Mitzvah by reaching out to other kids with disabilities to bring them into the social world of gaming – to the amazingly vigorous and long-lived Bea Klier, mother of Peter, born when FD was just starting to be understood. Bea, at 102, is helping us launch our new campaign, Forever Devoted in memory and gratitude for the support she received from the Foundation for her son many years ago. Efforts at raising both funds and awareness range from golf outings on Long Island, in Edmonton and in Chicago (along with sold out mah jongg in the Windy City!), to the NextGen group's spinning event, and of course the many individuals who have helped generate support through their singular efforts, from running a marathon to celebrating a birthday through donations via Facebook.

Finally, we are really excited and profoundly grateful to introduce our new extremely talented and devoted nurse practitioners at the FD Center, Zenith Kahn and Kaia Dalamo, who are meeting so many people in our community as routine exams or particular medical issues take them to the NYU Treatment Center. We are impressed at their dedication to achieving the standards of excellence and compassionate care set by prior staff.

We look forward to hearing from you in 5780!

Faye Ginsburg, President



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It's a Win/Win for You and FD!

Check out Smile.Amazon.com

This holiday season and throughout the year, if you make a purchase on Amazon, you'll be able to directly impact the FD community. Simply go to:

1. smile.amazon.com
2. When prompted, choose to support Dysautonomia Foundation, Inc.
3. Happy shopping!

Are We Connected?

If you are not receiving email communications from the Foundation, we may not have your current email address. If you'd like to add or update your email address, please send an email to info@famdys.org. In the subject line, include your full name and the words "add my email." We look forward to connecting!

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#FDMatch19 Raises More Than \$250,000

The Foundation recently launched #FDMatch19, our annual crowdfunding campaign. A crowdfunding campaign is when a group of similarly motivated individuals fundraise online for a common goal/passion, like FD. We set an ambitious goal of raising \$300,000 in 30 days, and at press time have raised more than \$250,000!

With the participation of fundraisers and supporters throughout the community, as well as our generous matching gift sponsors, we are making a difference in the lives of those affected by FD. Funds raised through #FDMatch19 will support:

- **patient visits with medical specialists**, such as a pulmonologist, who are trained in the unique challenges of caring for a person with FD;
- the Foundation's **oxygen equipment rental program**, which provides free access to oxygen concentrators for people with FD who cannot travel on an airplane without it;
- **annual check-ups** with the renowned Dysautonomia Center staff who conduct a variety of assessments and tests, while also collecting critical data for the FD Natural History Study;
- the cost of medical care provided at the Center and **not reimbursed by insurance**.

Interested in learning more and making YOUR impact in the FD community? Contact Natasha Weinstein via email at nweinstein@famdys.org and mention #FDMatch20!



Enjoying games at FD Day (l to r): Rebecca Newman, Frannie Cohen and Sarah Zucker

FD Day 2019 Better Than Ever

On June 2nd, more than 150 FD family members and friends gathered from around the world to learn about new developments in FD care and treatment at the 34th annual FD Day in New York City. The day was filled with long-awaited reunions, informative presentations by renowned physicians and exciting activities for the kids. View videos of the presentations here: <https://familialdysautonomia.org/resources/video-galleries/fd-day-2019>



2019 winner of the Distinguished FD Adult Award Chanie Profesorke, with her sister Devorah



Many Thanks To Our Creative FD Fundraisers!

- From July 21st through July 27th, **Mike Zucker** was busy biking across Iowa for RAGBRAI, the Des Moines, Iowa Register's Annual Great Bicycle Ride Across Iowa. Heading into its 46th year, RAGBRAI is the oldest, largest and longest multi-day recreational bicycle touring event in the world. Along with a group of friends, Mike biked 468 miles and raised \$3,642 in honor of his daughter **Sarah**, who has FD.
- **Ryan Lane** ran the NYC marathon on November 3rd in honor of our very own **Perry Goldberger**. He surpassed his goal to raise \$20,000 to benefit FD.
- **Andrew Sigman** hosted a fundraiser on Facebook this summer in honor of his birthday and brought in \$701 for FD.

Long Term Collaboration Helps FD Center Gain International Recognition

Dr. Joel Gutierrez, an expert in clinical neurophysiology from the Cuban Institute of Neurology and Neurosurgery, has been working with the FD Center for more than a decade to study nerve function in patients with FD. By measuring electrical changes, he is able to map nerve connections in the body and identify why the nerves are malfunctioning. Being able to do this requires a painstaking knowledge of human anatomy, electrophysiology, and clinical neurology.

The Foundation has supported a Visiting Professorship Program at the Center since 2009. Each year, Dr. Gutierrez has come from Havana, Cuba to visit the Center, mapping reflex nerve pathways in patients with FD over time. He has helped families understand why patients with FD have trouble swallowing, experience a dulled sense of pain, injure their corneas, and struggle to walk. This knowledge has helped the team develop programs specifically designed for the treatment of patients with FD.

According to **Dr. Lucy Norcliffe-Kaufmann**, "Dr. Gutierrez is a very important part of our extended FD clinical research program. He's helped us gain international recognition for FD among the electrophysiology field." Last month, he received the 2019 Annual Award from the Cuban Academy of Sciences. This is the most important award given to scientific

results in Cuba and it is highly recognized in the area. The work presented was a compilation of many research studies developed at the FD Center during the last 10 years led by Dr. Gutierrez.

Dr. Gutierrez has followed almost 30 patients with FD for the last 10 years testing them on an annual basis. "We need patients with FD to come back to be re-examined," he explains. "We are collecting important information that we use to understand why patients have distressing symptoms." Adds Dr. Norcliffe-Kaufmann, "The trigeminal nerve provides sensory information from the head and neck. Dr. Gutierrez has shown that because of a problem with the trigeminal nerve, patients with FD fail to blink and protect their corneas, which makes them prone to injury."

In clinical practice, nerve conduction studies are used by neurologists to diagnose a variety of medical conditions. The test itself is short and involves applying a small current to the skin and measuring muscle twitch. This painless, quantifiable test is used frequently in the treatment of patients with peripheral neuropathies. Explains Gutierrez, "It helps us understand acute problems like drop foot or limb numbness. If we can understand how the function of these nerves changes over time we can plan ways to protect and restore them."

FD Family Encourages Others To Participate In Trials

This past summer, **Barrie** and **Rick Rappaport** and their 24-year-old daughter **Michelle**, who has FD, visited the Dysautonomia Center for an annual visit. According to Barrie, “Even though it’s very expensive for us, we try to get to New York when we can so that the doctors at the Center know Michelle. If a crisis occurs, they will know who she is. We are now trained to ask the docs at the Center what they are working on to see if perhaps Michelle can benefit from that too.”

Since FD impacts each person differently, the Rappaports understand that what works for one patient doesn’t always work for another. “The Center can’t help with new things to try on FD patients unless they have people to try them on,” explains Barrie. “The Center and the FD Foundation invest a lot of money into this disease and I am very grateful for that. Because FD is such a rare disease, there are not enough patients to do a double-blind placebo study so we all need to get on board and take our kids to be seen and studied.”

About five years ago, Michelle participated in a trial and started taking carbidopa, a new medication that has made a big difference in her quality of life. Adds Barrie, “It’s very costly and we have to fight insurance to cover it but it’s worth it.”

The Rappaports hope other FD families will follow their lead and bring their kids to the Center for annual visits as well as participate in clinical studies. “It’s all very anecdotal because of our size. Our families should be open to talking about advances and participating in trials. If not us, then who?” says Barrie.



Barrie and Michelle Rappaport

Dr. Lucy Norcliffe-Kaufmann’s Poster Featured at NORD’s RARE Summit in Washington DC

Congratulations to **Dr. Lucy Norcliffe-Kaufmann**, Associate Director of the NYU Dysautonomia Center, whose poster, “Carbidopa as a novel treatment for afferent baroreflex failure: A double-blind randomized phase II clinical trial,” was featured at the National Organization for Rare Disorders (NORD) Rare Diseases and Orphan Products Breakthrough Summit. More than 900 members of the rare disease community, including patient advocacy groups, government, industry and academia attended the conference, held in Washington DC in October.

The FD Website Has a New Look

When you visit **famdys.org** you will see that the Foundation’s website has been completely overhauled to include updated information about FD. You will also notice that the site is enhanced visually with many striking photos taken by **Rick Guidotti** of Positive Exposure.

Visit our website to learn the latest news about FD, reserve oxygen for travel, find out about upcoming events, make a donation or purchase an item from our on-line store.

FD Latest News

For the latest news from the Dysautonomia Center at NYU Langone, check out their blog at <https://dysautonomiacenter.com>

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FD Foundation Achieves Highest Ratings

We are proud to announce that the FD Foundation has achieved the highest ratings from both **Charity Navigator** and **GuideStar**.

Our **Four-Star Rating** from Charity Navigator is based on both financial health and accountability and transparency. This rating shows our donors how efficiently the Foundation will use their support, how well we have sustained our programs and services over time, and our level of commitment to accountability and transparency.

We've also earned a **2019 Platinum Seal of Transparency**, the highest level of recognition offered by GuideStar, the world's largest source of nonprofit information. To reach the Platinum level, the FD Foundation added extensive information to its GuideStar Nonprofit Profile, demonstrating our commitment to transparency and to giving donors and funders meaningful data to evaluate our performance.



Great Minds Meet At NYU

On October 11, scientists from across the country who are working on various aspects of FD research met at NYU Langone Medical Center to share their findings and the current status of their work. The goal of the FD Research Consortium, sponsored by the FD Foundation, was to gain a better understanding of the status of each person's research, the anticipated timeline and outcome, and outstanding funding needs. Most importantly, by bringing everyone together in one room, we were able to stimulate cooperation and collaboration among all those working on FD.

For an ultra-rare disease, we are very fortunate to have so many outstanding scientists and clinicians focused on new treatments for FD, as well as a number of potential therapies in the pipeline focused on various aspects of the disorder:

- **Mike Brownstein** (chair of the Foundation's Scientific Advisory Board) proposes to study **SRX246**, a vasopressin V1A receptor antagonist which may decrease anxiety and reduce nausea in people with FD. Additionally, **BGP-15**, a disease-modifying candidate, is known to improve mitochondrial function and may be useful in FD.
- **Horacio Kaufmann, Lucy Norcliffe-Kaufmann, Jose-Alberto Palma** and the team at the **NYU Dysautonomia Center** are looking at whether **carbidopa (Lodosyn)** and/or **Dronabinol** can be effective against nausea/retching/vomiting attacks.
- **Adrian Krainer** and his team at Cold Spring Harbor Laboratories, including **Young Jin Kim**, are studying **antisense oligonucleotides**, which could potentially modulate splicing and produce normal mRNA for the FD gene.
- **Frances Lefcort** and her team at Montana State University, including **Claudio Punzo** at U Mass Medical School, are developing **adeno-associated virus (AAV) gene therapy** to deliver normal copies of the FD gene to eye cells to try to improve visual function.
- **Sue Slaughaupt** and her team at Harvard/MGH, including **Elisabetta Morini**, are working with pharmaceutical company PTC to identify a "**super kinetin**" that will have positive impact on gene splicing with reduced unpleasant side effects.

We ended the day with a sense of hope and optimism for FD research and treatment; and we look forward to continuing to share news and updates with the FD community.



Golf Outings Raise Funds and Awareness for FD

LONG ISLAND: The 23rd Annual FD Golf Outing on Long Island on May 20th was a swinging success. Thanks to all those who came together to support and raise funds for those with FD. The sun shone throughout the day, the food was great and all the golfers had a blast. A special thanks to our Golf Chairs **Paul Wexler, Steve Fass, Steve Kietz** and **Rachel Schlau** for their hard work and dedication.

CHICAGO: Congratulations to chairs **Gregg and Laura Meyers** of Buffalo Grove, IL, parents of **Sophie Meyers**, age 17, for another successful event to benefit FD. The 16th Annual Golf Classic, and the 11th Annual Ladies Lunch & Play held on July 29 at Ravinia Green Country Club in Riverwoods, IL, brought together more than 300 people and raised more than \$60,000 for the FD Foundation. Thanks to hard working co-chairs **Corrie Delevitt** and **Joey Rosen**, the Ladies Lunch & Play continues to be a SOLD OUT event!

Want to organize your own Lunch & Play? If you like cards, why not create your own FD benefit? Whether it's canasta, rummy, bridge or mahjong, games are a great way to bring people together while raising money at the same time. We can help you plan the event and provide fundraising tools. Give us a call at 212-279-1066 and we will walk you through it!

CANADA The **Stevie Schwartzberg** Memorial Golf Tournament was held on September 8th in Edmonton, Alberta, at the Links Golf Club in Spruce Grove. Stevie's parents, **Jack, Rowena** and his sister **Daryl**, "have committed to celebrating Stevie and honoring his legacy by raising money for the Montreal chapter of FD."

Although the weather was cold, windy and generally miserable, there were 43 hole sponsors and all but two golfers showed up, while 190 friends attended the dinner. According to Jack, "It was a home run. We blew it out of the water. We expected to raise \$50,000 but we hit \$100,000 CAD which is equivalent to \$75,000 in the U.S. and donations are still coming in."

Proceeds from the Outing will support the newly established **Stevie Schwartzberg Mental Health Program** at the Dysautonomia Center at NYU. The program is coordinated by **Lily Armstrong**, a mental health counselor who had a very special relationship with Stevie. Lily offers psychotherapy sessions via telephone to people with FD across North America. The Schwarzbargs invited Lily to travel to Edmonton to speak at the Outing about the growing program and its impact on people with FD. Jack Schwartzberg observed, "Lily is a superstar. She added a whole new dimension to the event, and we were so happy to spend time with her as she is a beautiful soul."



Golf Co-Chair Rachel Schlau and her foursome enjoy a beautiful day at Glen Oaks Club.



Gregg and Sophie Meyers



Stevie Schwartzberg enjoying a day on the golf links.



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Tuesday, December 3

A national annual day of giving held the Tuesday after Thanksgiving.

Americana Manhasset's 24th annual Champions for Charity® 2019

Sunday, December 5 -7

Shopping Event, Long Island, NY

24th Annual FD Golf Outing

Monday, May 18

Glen Oaks Club, Old Westbury, NY

35th Annual FD Day

Sunday, June 7th

NYU Langone

FD Newsletter Fall 2019

Written by: Lisa Denburg

Edited by: Lanie Etkind, Natasha Weinstein and Faye Ginsburg

ON THE COVER

"Tear-Shaped" by Gabi Jassie, winner of the self portrait category of the 2019 photo contest at FD Day.

If you have a photo you'd like to share for a future issue of DYS/COURSE, please send it to letkind@famdys.org.

The Familial Dysautonomia Foundation is a 501 (c) (3) non-profit organization dedicated to funding treatment of, research on and awareness about familial dysautonomia, a rare, life-threatening, Jewish genetic disease that affects the autonomic nervous system.

A copy of our latest annual report may be obtained from the FD Foundation (315 W. 39th St., Ste. 701, New York, NY 10018) or from the New York State Attorney General's Charities Bureau (28 Liberty Street, 15th Floor, New York, New York 10005).