A YEAR WHEN AN ICE-FILLED BUCKET SUCCESSFULLY CHANGED THE WORLD
Dear friend,

2014 was a pivotal year for our community. For the first time in the nearly 75 years since Lou Gehrig’s passing, the US—and the world—was talking about ALS. Thanks to the efforts spurred by Pete Frates and Pat Quinn—two young men living with the disease—the global phenomenon known as the “Ice Bucket Challenge” helped bring global awareness to ALS and much needed funding to the ALS research community.

The ALS Therapy Development Institute independently garnered $4 million from the Ice Bucket Challenge, and all of that funding was immediately allocated to research projects in our lab. We directed funds towards opportunities that would accelerate the pace of finding a treatment and cure for ALS: $1 million went directly towards the first ever precision medicine program for ALS, and $3 million went to the development of two clinical trial programs.

2014 was the most successful fundraising year in the Institute’s history, and it has been equally significant in terms of research progress. This is YOUR lab, and we’re incredibly grateful for your generosity and support to see our mission through, to end ALS.

Sincerely,

Steve Perrin
CEO and CSO
ALS Therapy Development Institute
Successfully integrated the Augie’s Quest brand and team into the ALS Therapy Development Institute bringing new leadership and fundraising experience.

The Tri-State Trek bike ride to end ALS surpasses fundraising milestone, raising $796,000 for ALS research.

Raised $4 million through Ice Bucket Challenge phenomenon created by Institute supporters Pete Frates, Pat Quinn and Anthony Carbajal.

Enrolled first 20 PALS into Precision Medicine Program, announced enrollment expanded to 300 thanks to Ice Bucket Challenge funding.

Ales for ALS™ program expanded to 65 brewers and 2 beer fests, raising $331,555 for ALS research.

Announced $3 million in Ice Bucket Challenge funding to be spend on clinical stage programs targeting CD40L (w/Anelixis) and misfolded SOD1 (w/Neurimmune).

Enrolled 30 PALS in Phase 2A clinical trial of TDI-132 (Gilenya®).

Annual Leadership Summit hosted by the Institute attracts speakers from Cytokinetics, Voyager Therapeutics, PatientsLikeMe, PoliIwog Holdings, The Scripps Research Institute and the University of Florida.
It began with two young men who had been diagnosed with ALS: Pete Frates and Pat Quinn. Pete Frates was a 29-year-old from Beverly, MA, who was a Boston College graduate and a star athlete as a former captain of the BC baseball team. Pat Quinn was a 30-year-old from Yonkers, NY, a graduate of Iona College. Both Pete and Pat befriended one another shortly after their diagnoses, and both envisioned changing their prognosis with the disease and raising awareness of ALS to the masses. It was their friends and networks who began the challenge; then sports figures, celebrities, and politicians participated; and soon afterwards, it was a global phenomenon dominating everyone’s Facebook news feeds and social consciousness.

Almost at the height of the Ice Bucket Challenge, another young face of ALS emerged: Anthony Carbajal. Anthony was a 26-year-old who was diagnosed with ALS earlier that year. Anthony was all too familiar with the disease; his family carries a genetic form of ALS, which has affected both his mother and grandmother. Aside from sharing another video of getting doused with water, Anthony’s Ice Bucket Challenge video stood out from others, bringing awareness of what the disease looks like by also sharing his personal story with the disease and creating his call to action to donate to the ALS Therapy Development Institute. His video was picked up by Upworthy, CNN, NBC and other news media outlets, and he even did an Ice Bucket Challenge with Ellen DeGeneres live on her show! More importantly, people saw his poignant video and donated to ALS research at the Institute to help him and all others affected by the disease to one day have effective treatments and a cure.

Thanks to the efforts begun by these young men, the ALS Therapy Development Institute independently raised almost $4 million from the Ice Bucket Challenge in 2014. Today, all of those donations have been spent on promising programs with the most opportunity to make an impact on ALS.

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**THE YEAR OF ICE BUCKETS**

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Defined by the National Research Council, precision medicine refers to the “tailoring of medical treatment to the individual characteristics of each patient. It is the ability to classify individuals into subpopulations that differ in their susceptibility to a particular disease, in the biology and/or prognosis of those diseases they may develop, or in their response to a specific treatment. Preventive or therapeutic interventions can then be concentrated on those who will benefit, sparing expense and side effects for those who will not.”

At the ALS Therapy Development Institute, we have long believed that precision medicine is essential to the future advancement of treatments and cures for ALS. The ALS Therapy Development Institute began planning its Precision Medicine Program in 2013 and announced a call for volunteers in August 2014. The goal of the Precision Medicine Program is to identify subtypes of ALS and the specific compounds (therapies/drugs) that treat each type to advance the most effective treatments into clinical trial.

The Institute’s Precision Medicine Program integrates a patient’s genetic code obtained by a full sequence of their genome, a patient’s phenotypic data characterized by monthly self-reporting questionnaires, unbiased accelerometer data measuring motion, voice recordings, and the creation of an induced pluripotent stem cell line (iPS).

The Institute is providing all participants with access to the data generated using a secure online portal. Participants are able to track their disease progression by viewing changes in accelerometer, speech and other self-reported data, by seeing results of their genome sequencing in relation to the currently known 30+ ALS-associated genes, and viewing images of their own skin and iPS cell lines created at the Institute.

When the Institute first launched the program, it was expected to enroll up to two dozen people. However, with funding from the social media phenomenon, the Ice Bucket Challenge, the Institute was able to expand enrollment to hundreds, enabling more people living with the disease to actively participate in the discovery of effective treatments and cures for ALS.
Below is a graphical representation of revenue and expenses for the last four years, 2011-2014. As always, ALS Therapy Development Institute is committed to transparency in our research, in our fundraising, and in our financial information. We are proud of our continued achievement, year after year, to spend as much funding as possible every day on research toward our single mission: to end ALS. More information is available on our website at als.net.

**ASSETS**

**CURRENT ASSETS**
- Cash and Cash Equivalents: $8,599,384
- Pledges & Accounts Receivable: $864,014
- Other: $279,514

**OTHER ASSETS**
- Pledges Receivable: $543,637
- Property & Equipment, net: $876,560
- Patents: $185,961

**NET ASSETS EOY 2014**: $11,349,070

**LIABILITIES & NET ASSETS**
- Current Liabilities: $2,266,106
- Long Term Liabilities: $375,736
- Net Assets: $8,707,228

**TOTAL LIABILITIES & NET ASSETS**: $11,349,070

**OPERATING INCOME**
- Grants: $188,000
- Special Events, net: $9,255,351
- Contributions: $4,314,317
- Released from Restrictions: $530,000
- Fee for Service: $435,914
- Donated Goods & Services: $12,751
- Interest: $5,151

**NET PUBLIC**: $14,741,484

**OPERATING EXPENSES**

**PROGRAM**
- R&D
  - Science: $7,696,978
  - Informatics: $400,761
  - Patient Services: $75,508
  - Communications: $1,389,898
  - Business Development: $414,361

**SUPPORT**
- General: $585,196
- Fundraising: $939,459

**TOTAL PROGRAM**: $9,977,506

**TOTAL SUPPORT**: $1,524,655

**TOTAL EXPENSES**: $11,502,161

**TOTAL SPENT**

<table>
<thead>
<tr>
<th></th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
<th>2014</th>
<th>TOTAL SPENT</th>
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<td>PROGRAM SERVICES</td>
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<td>SUPPORT SERVICES</td>
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For the fiscal year ending December 31, 2014 ALS TDI recognized more than $14.7 million in contributions to advance its singular and profound mission: discover and develop effective treatments for ALS patients as soon as possible. Compared to the previous year, this represented a significant increase in support, which was due in large part to the funds received through the Ice Bucket Challenge.

A full breakdown of our assets, liabilities, revenue, and expenses is below. For a complete copy of our IRS Form 990 or Independent Auditors Report, please visit our website at als.net or call us at 617.441.7200.

**FINANCIAL REVIEW**

2011-2014: A FINANCIAL COMPARISON

2014 Ice Bucket Challenge
$4 million raised at ALS Therapy Development Institute
from 51,868 US donors and 10,826 international donors from 126 countries

87 cents per dollar is spent on research and programs