PPMI
Recruitment, Enrollment and Retention

Update to the PPMI Annual Meeting
May 5, 2011

Danna Jennings, R&R Working Group Chair
PPMI
Recruitment, Enrollment and Retention

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Study Status and Recruitment Challenges

• 17 sites are actively recruiting
  – Most sites online Fall of 2010 with the remainder being activated winter/spring 2011
  – A couple sites are expected to come online this summer/fall

• Challenges in start-up and recruitment
  – Significant start-up delays as a result of regulatory approvals, organizational requirements, etc
  – Developing new recruitment strategies for observational study design
  – Learning curve for arranging logistics for study visits
  – Limited and lack of availability of DaTSCAN
Revisiting our Recruitment and Retention Goals

• **Recruitment**: Enroll 1 PD subject a month and 1 control every other month

• **Retention**: Keep subjects engaged in the study so that they continue to participate in study visits over time
Recruitment and Enrollment in the next 17 months
Recruitment Progress to Date
(as of May 1, 2011)

- 21% of 42/200 controls are enrolled (48% consented*)
- 15% of 61/400 Parkinson subjects are enrolled (36% consented*)

* Excluded/Declined/withdrawn subjects have been removed from these and all consented calculations throughout this presentation
<table>
<thead>
<tr>
<th>US Sites</th>
<th>Activation Status</th>
<th>Consented (excluding declined/withdrawn)</th>
<th>Enrolled</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>PD</td>
<td>Controls</td>
</tr>
<tr>
<td>Baylor (Houston)</td>
<td>✓ Active</td>
<td>9</td>
<td>4</td>
</tr>
<tr>
<td>BU (Boston)</td>
<td>✓ Active</td>
<td>9</td>
<td>4</td>
</tr>
<tr>
<td>Cleveland Clinic (Cleveland)</td>
<td>Pending Activation (est April)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Emory (Atlanta)</td>
<td>✓ Active</td>
<td>11</td>
<td>3</td>
</tr>
<tr>
<td>IND (New Haven)</td>
<td>✓ Active</td>
<td>15</td>
<td>8</td>
</tr>
<tr>
<td>Hopkins (Baltimore)</td>
<td>✓ Active</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Northwestern (Chicago)</td>
<td>✓ Active</td>
<td>13</td>
<td>5</td>
</tr>
<tr>
<td>OHSU (Portland)</td>
<td>✓ Active</td>
<td>15</td>
<td>9</td>
</tr>
<tr>
<td>The PI (Bay Area)</td>
<td>✓ Active</td>
<td>11</td>
<td>2</td>
</tr>
<tr>
<td>Sun Health (Phoenix)</td>
<td>✓ Active</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>UAB (Birmingham)</td>
<td>✓ Active</td>
<td>10</td>
<td>9</td>
</tr>
<tr>
<td>UCSD (San Diego)</td>
<td>Pending Activation (est April/May)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>U Penn (Philadelphia)</td>
<td>✓ Active</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>U Rochester (Rochester)</td>
<td>✓ Active</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>U South FL (Tampa)</td>
<td>✓ Active</td>
<td>8</td>
<td>5</td>
</tr>
<tr>
<td>U Washington (Seattle)</td>
<td>✓ Active</td>
<td>10</td>
<td>3</td>
</tr>
</tbody>
</table>
## Site Performance to Date - Europe

<table>
<thead>
<tr>
<th>EU Sites</th>
<th>Activation Status</th>
<th>Consented (excluding declined/withdrawn)</th>
<th>Enrolled</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>PD</td>
<td>Controls</td>
</tr>
<tr>
<td>Innsbruck U (Austria)</td>
<td>✓ Active</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Paracelsus Klinic (Kassel/ Marburg Germany)</td>
<td>✓ Active</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>U Naples (Naples)</td>
<td>Pending Activation (est Summer)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>U Tuebingen (Tuebingen)</td>
<td>✓ Active</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Imperial College (London)</td>
<td>Pending Activation (est Fall)</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>
Recruitment Strategies and Activities

• Site Efforts
  – Many good leads from clinic practices
  – Community outreach (support groups, symposia, physician networks, etc)

• MJFF strategies
  – Produced complete suite of recruitment materials
  – Salons hosted in 15 US cities
  – Physician mailings sent in 5 markets
  – Support group mailings planned for summer/fall

• Media
  – Over 75 major media hits on PPMI— including
    • CNN
    • The New York Times
    • The Chicago Tribune
    • Fox News (National and several local affiliates)
    • The LA Times, Lancet Neurology
    • USA Today, etc
Successful Recruitment Strategies

- A multi-pronged approach
- PI actively involved in recruitment
- Physician referral network development – this is a long-term game that requires multiple contacts
- Leverage internal resources at your site- Remind colleagues to refer, leverage affiliations with your University, etc.
- Make media happen- you identify a subject to represent your site to the media; we will do the rest
PPMI Media Highlights Reel
Interest in PPMI through central recruitment channels

19,244 unique visitors to michaeljfox.org/PPMI
5,564 unique visits to PPMI-info.org

110 direct inquiries into the call center
683 people from MJF.org/PPMI complete web form to learn more

+ an additional 615 calls directly to site

237 people referred to site

115 faxes have been returned
19 people (17%) have been screened
96 individuals not eligible or declined participation
Sources for Web and Call Center Inquiries

Advocacy Organization
Support group
Family or Friend
Other specialist
Primary care physician
Site personnel
Event
Online News/Blog
Web Ad
Trial Search Website
Clinical Site Website
PPMI Website
MJFF website
MJFF Email
MJFF Newsletter
TV/Radio Story
TV/Radio Ad
Newspaper/Magazine...
Newspaper/Magazine Ad

Source distribution by month:
- Apr
- Mar
- Feb
- Jan
- Dec
- Nov
Recruitment Sources for Consented Participants

- Advocacy Org
- Family or Friend
- MJFF Publicity
- Neurologist
- Newspaper Article
- PI Newsletter
- Primary Care
- Community Event
- Study Website
- Study Web Ad
- Site Personnel
- Self
- Trial Search
- TV/Radio
- Support Group
- TV/Radio

Apr
Mar
Feb
Jan
Dec
Nov
Oct and prior

0%
5%
10%
15%
20%
Awards for Site Performance

• Most subjects consented per month
• Most PD subjects enrolled
• Most Controls enrolled
• Best recruitment start in Europe
• Most creative and effective outreach to referring practitioners
• Most subjects consented
• Best (multi-pronged) community outreach plan
Most Subjects Consented per Month

• This site has consented an average of 2.3 subjects per month since being activated in September 2010

• They also have the second most actively enrolled subjects in the study
Most Subjects Consented per Month

• And the winner is....

[Certificate Image]

CERTIFICATE OF RECOGNITION

This certificate is awarded to

OHSU

In gratitude for your involvement:

Michael J. Fox

Katie Hood

CEO, Michael J. Fox Foundation for Parkinson’s Research
Most PD Subjects Enrolled

- There was a tie between two sites for this award, but since OHSU already won...
- This site has a whopping 9 PD subjects enrolled in the study!
Most PD Subjects Enrolled

• And the winner is....

CERTIFICATE OF RECOGNITION

This certificate is awarded to

UAB

In gratitude for your involvement:

Michael J. Fox

Katie Hood

CEO, Michael J. Fox Foundation for Parkinson’s Research
Most Controls Enrolled

• This site has enrolled 6 control subjects!
• They also take the cake for the most enrollments in a month with 9 enrollments happening within one 4-week period!
Most Controls Enrolled

• And the winner is....

CERTIFICATE OF RECOGNITION
This certificate is awarded to

Emory

In gratitude for your involvement:

Michael J. Fox

Katie Hood
CEO, Michael J. Fox Foundation for Parkinson's Research
Best Recruitment Start in Europe

• This site got started with a bang—one media story generated 55 inquiries about the study in the first 2 weeks

• 3 controls have been consented as a result
Best Recruitment Start in Europe

• And the winner is....

Innsbruck
Most Creative and Effective Outreach to Referring Practitioners

• This site has conducted outreach to their internal referral network and been successful in building a referral network outside of their organization

• They have also had an influx of inquiries as a result of media
Most Creative and Effective Outreach to Referring Practitioners

• And the winner is....

Northwestern

In gratitude for your involvement:

Michael J. Fox

Katie Hood
CEO, Michael J. Fox Foundation for Parkinson’s Research
Most Subjects Consented

• This site has consented 21 subjects for the study and enrolled a whopping 13 to date
• Even though they were the first site activated, their average number of subjects consented per month has ranked within the top 5 consistently throughout the study
Most Subjects Consented

• And the winner is....

CERTIFICATE OF RECOGNITION

This certificate is awarded to

IND

In gratitude for your involvement:

Michael J. Fox
Katie Hood
CEO, Michael J. Fox Foundation for Parkinson’s Research
Best (multi-pronged) Community Outreach Plan

• This site is getting out there—speaking at support groups, placing newsletter articles, presenting at events, and getting some well-targeted media
Best (multi-pronged) Community Outreach Plan

• And the winner is....

CERTIFICATE OF RECOGNITION

This certificate is awarded to

The PI

In gratitude for your involvement:

Michael J. Fox

Katie Hood
CEO, Michael J. Fox Foundation for Parkinson’s Research
The Road Ahead:
Two key challenges for sites

• **Recruitment**: Keeping the pipeline full
  – The study is 1/6 of the way there, but the excitement around the launch is waning.
  – Sites must continue to evolve their recruitment planning and revisit key strategies

• **Retention**: Maintaining the stamina and loyalty of enrolled subjects
  – Update from Retention Pre-Session yesterday
Questions?