PPMI
Recruitment, Enrollment and Retention

Update to the PPMI Annual Meeting
May 3, 2012

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PPMI Recruitment Retention Working Group

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• Emily Flagg
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• Christine Hunter
• Danna Jennings (Chair)
• Claire Meunier
• Tanya Simuni
• Carlie Tanner
• Cathi Thomas
Revisiting our Recruitment and Retention Goals

• **Recruit** 400 *de novo* and 200 control subjects
  – **Site Goal**: Enroll 1 PD per month and 2 more controls this year

• **Retain** subjects by keeping them engaged to participate in study visits over time
  – **Site Goal**: Remain connected and continue to cultivate volunteers as key partners in the study
Recruitment progress to date

- Control recruitment has been easier than anticipated, exceeding enrollment projections
- PD recruitment has been more challenging than expected, but progress continues to be made.

With every site enrolling at least one PD subject a month, we can complete PPMI recruitment by the end of the year.
Recruitment Progress to Date
(as of April 30, 2012)

- 75% (149/200) of controls are enrolled (77% consented*)
- 51% (204/400) of Parkinson subjects are enrolled (58% consented*)

* Excluded/Declined subjects have been removed from these and all consented calculations throughout this presentation
# Site Performance to Date - US

## Meeting PD goal
(>1 PD Enrollments/Month)

<table>
<thead>
<tr>
<th>Sites</th>
<th>PD</th>
<th>Controls</th>
<th>PD Enr/mon</th>
</tr>
</thead>
<tbody>
<tr>
<td>IND (New Haven)</td>
<td>28</td>
<td></td>
<td>1.52</td>
</tr>
<tr>
<td>Cleveland Clinic (Cleveland)</td>
<td>11</td>
<td></td>
<td>1.45</td>
</tr>
<tr>
<td>Emory (Atlanta)</td>
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<td></td>
<td>1.41</td>
</tr>
<tr>
<td>U Washington (Seattle)</td>
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<td></td>
<td>1.35</td>
</tr>
<tr>
<td>OHSU (Portland)</td>
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<tr>
<td>UAB (Birmingham)</td>
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<td></td>
<td>1.26</td>
</tr>
<tr>
<td>U South FL (Tampa)</td>
<td>13</td>
<td></td>
<td>1.23</td>
</tr>
<tr>
<td>U Pennsylvania</td>
<td>11</td>
<td></td>
<td>1.16</td>
</tr>
<tr>
<td>BU (Boston)</td>
<td>10</td>
<td></td>
<td>1.01</td>
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## Have not yet met PD goals
(<1 PD Enrollments/Month)

<table>
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<th>Sites</th>
<th>PD</th>
<th>Controls</th>
<th>PD Enr/mon</th>
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<tbody>
<tr>
<td>U Rochester (Rochester)</td>
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<td></td>
<td>0.94</td>
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<tr>
<td>Northwestern (Chicago)</td>
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<td></td>
<td>0.94</td>
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<tr>
<td>The PI (Bay Area)</td>
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<td></td>
<td>0.91</td>
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<td>Baylor (Houston)</td>
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<td>UCSD (San Diego)</td>
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<td>0.71</td>
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<tr>
<td>Hopkins (Baltimore)</td>
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<td></td>
<td>0.71</td>
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<tr>
<td>Banner Health/APDC</td>
<td>6</td>
<td></td>
<td>0.49</td>
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Site Performance to Date - International

<table>
<thead>
<tr>
<th>Sites</th>
<th>PD</th>
<th>Controls</th>
<th>PD Enr/mon</th>
</tr>
</thead>
<tbody>
<tr>
<td>U Tuebingen (Tuebingen)</td>
<td>11</td>
<td>9</td>
<td>1.64</td>
</tr>
<tr>
<td>Paracelsus Klinik (Kassel/ Marburg Germany)</td>
<td>7</td>
<td>11</td>
<td>1.22</td>
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Meeting PD goal
(>1 PD Enrollments/Month)

<table>
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<th>Sites</th>
<th>PD</th>
<th>Controls</th>
<th>PD Enr/mon</th>
</tr>
</thead>
<tbody>
<tr>
<td>Innsbruck U (Austria)</td>
<td>3</td>
<td>8</td>
<td>0.75</td>
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</table>

Have not yet met PD goals
(<1 PD Enrollments/Month)
Recruitment Strategies and Activities

• Site Efforts
  – Continued recruitment from clinic practices; consistent outreach and reminders to clinical colleagues and physicians who are affiliated with site, as well as cultivation of colleagues in the community who refer
  – Community outreach continues (support groups, symposia, physician networks, etc)
  – Partnerships with imaging teams to recruit non-site-referred DaT patients

• MJFF strategies
  – Physician salons to cultivate MD relationships at 6 sites; Sites are primary drivers of continuing to foster these relationships
  – Physician mailings sent in 8 markets; additional mailings planned for the rest of recruitment period
  – Veterans mailing to get male controls over 55 resulted in XX enrollments
  – 18 major media stories on the study
Sharing successful recruitment tactics

• **Physician Outreach and building a referral network**
  Zoltan Mari and Jim Leverenz

• **Creating process and structures for recruitment and patient referrals in your own clinic**
  David Standaert

• **Building a relationship with an imaging center**
  Robert Hauser

• **My role as a PI in boosting recruitment**
  Penny Hogarth

• **Coordinator Session: Report back**
  Karen Williams
New Strategies:
Focus on PD Recruitment

• Outreach to nuclear medicine facilities
• Consider bringing on a co-investigator at sites when appropriate
• Ambassador toolkit developed to equip PPMI patient committee and MJFF patient council to help spread the word
• Re-tooling web advertisement strategy to reach newly diagnosed who are seeking information online
• Media will continue in select markets where it has proven to result in PD screenings
• Fox Trial Finder is increasingly a resource for subjects as new volunteers register daily
• Working to develop a relationship with the VA system around PPMI and Fox Trial Finder
• Planning a veterans mailing to ask them to share info about the study with friends who are newly diagnosed
RetentionPolicy progress to date

<table>
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<tr>
<th></th>
<th>PD</th>
<th>Controls</th>
<th>SWEDDDs</th>
</tr>
</thead>
<tbody>
<tr>
<td>% retained</td>
<td>99.0% (n=2 withdrawn)</td>
<td>98.6% (n=2 withdrawn)</td>
<td>96.0% (n=1 withdrawn)</td>
</tr>
</tbody>
</table>

- Sites are doing a great job retaining subjects; Our goal is to maintain this success

- Reasons why subjects have withdrawn:
  - Unwilling to complete full battery of study tests and assessments
  - DaTscan indicated no dopamine deficit; subject did not want to be retained as a SWEDD
  - Subject lives too far away from site

- Tactics to retain subjects include:
  - Continued access to coordinators as primary resources of information for subjects
  - Giveaways at each visit
  - Site retention events (6 held to date; ~10 more planned for 2012)
Site Awards

Drumroll, please.....
PPMI Challenge: Recruit 3 PD patients from Jan 22 to now

- IND
- Cleveland Clinic
- Hopkins
- Emory
- Boston University
- OHSU
- U Wash/VA Puget Sound
- Tuebingen
- The PI
Sites that met the year 1 goal in less than 12 months

• Tie for 3rd place: IND and OHSU
  Met Year 1 Goal in 11.5 months

• Tie for 2nd place: U South Florida and U Washington
  Met Year 1 Goal in 10.75 months

• 1st place: Cleveland Clinic
  Met Year 1 Goal in 9.75 months
Most PD Consented

• 34 PD subjects have been consented at this site
• And the winner is....
Most PD Consents in one week

• 5 PD consented in one week
• And the winner is....

University of Tubingen
Most improved enrollment rate

- Last year at the meeting had .4* subjects enrolled per month coming into the study and now they have 1.8* per month

- And the winner is....

*rates from Jan – Apr of 2011 compared to Jan – Apr of 2012
The Road Ahead: Two key challenges for sites

• Recruitment: Keep the pipeline full
  – The study is over half way there
  – What can your site do to build momentum to recruit more PD subjects?

• Retention: Maintaining the stamina and loyalty of enrolled subjects
  – How can we step this up over time?
Questions?