

# PPMI

# Recruitment, Enrollment and Retention

Update to the PPMI Annual Meeting  
May 3, 2012

*Danna Jennings, R&R Working Group Chair*



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# PPMI Recruitment Retention Working Group

- Daniela Berg
- Sohini Chowdhury
- Carey Christensen
- Emily Flagg
- Katharina Gauss
- Christine Hunter
- Danna Jennings (Chair)
- Claire Meunier
- Tanya Simuni
- Carlie Tanner
- Cathi Thomas



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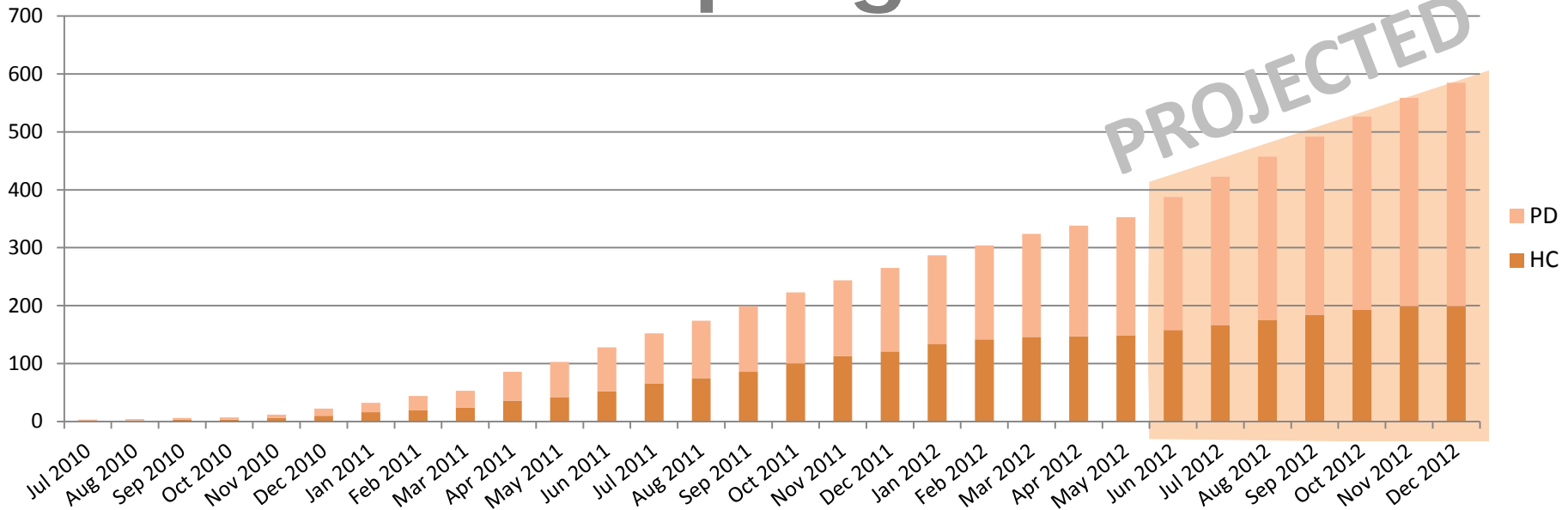


# Revisiting our Recruitment and Retention Goals

- **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

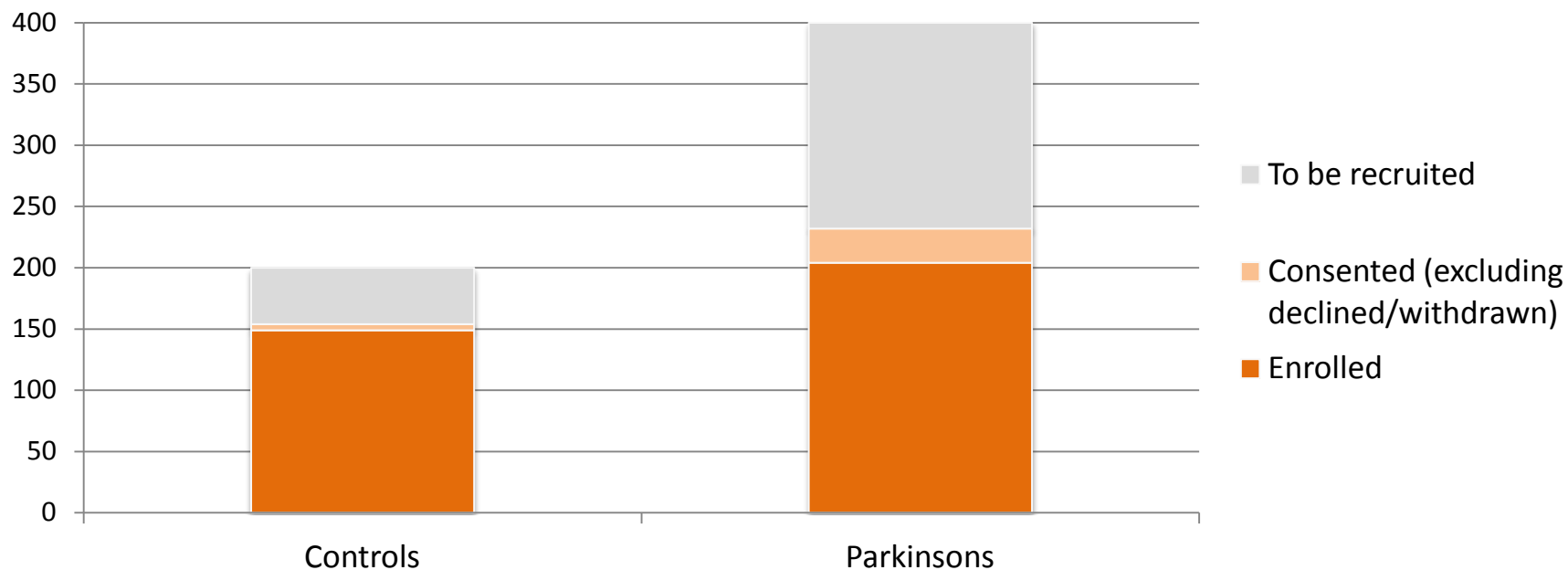


- Control recruitment has been easier than anticipated, exceeding enrollment projections
- PD recruitment has been more challenging than expected, but progress continues to be made.

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\*)



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\* 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)

Sites	Enrolled		
	PD	Controls	PD Enr/mon
IND (New Haven)	28	8	1.52
Cleveland Clinic (Cleveland)	11	5	1.45
Emory (Atlanta)	12	12	1.41
U Washington (Seattle)	14	7	1.35
OHSU (Portland)	15	10	1.28
UAB (Birmingham)	14	10	1.26
U South FL (Tampa)	13	8	1.23
U Pennsylvania	11	10	1.16
BU (Boston)	10	9	1.01

## Have not yet met PD goals (<1 PD Enrollments/Month)

Sites	Enrolled		
	PD	Controls	PD Enr/mon
U Rochester (Rochester)	10	7	0.94
Northwestern (Chicago)	10	9	0.94
The PI (Bay Area)	8	9	0.91
Baylor (Houston)	10	7	0.86
UCSD (San Diego)	3	3	0.71
Hopkins (Baltimore)	8	4	0.71
Banner Health/APDC	6	3	0.49



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# Site Performance to Date - International

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

<u>Sites</u>	<u>Enrolled</u>		
	<u>PD</u>	<u>Controls</u>	<u>PD Enr/mon</u>
U Tuebingen (Tuebingen)	11	9	1.64
Paracelsus Klinik (Kassel/ Marburg Germany)	7	11	1.22

## Have not yet met PD goals (<1 PD Enrollments/Month)

<u>Sites</u>	<u>Enrolled</u>		
	<u>PD</u>	<u>Controls</u>	<u>PD Enr/mon</u>
Innsbruck U (Austria)	3	8	0.75



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# 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



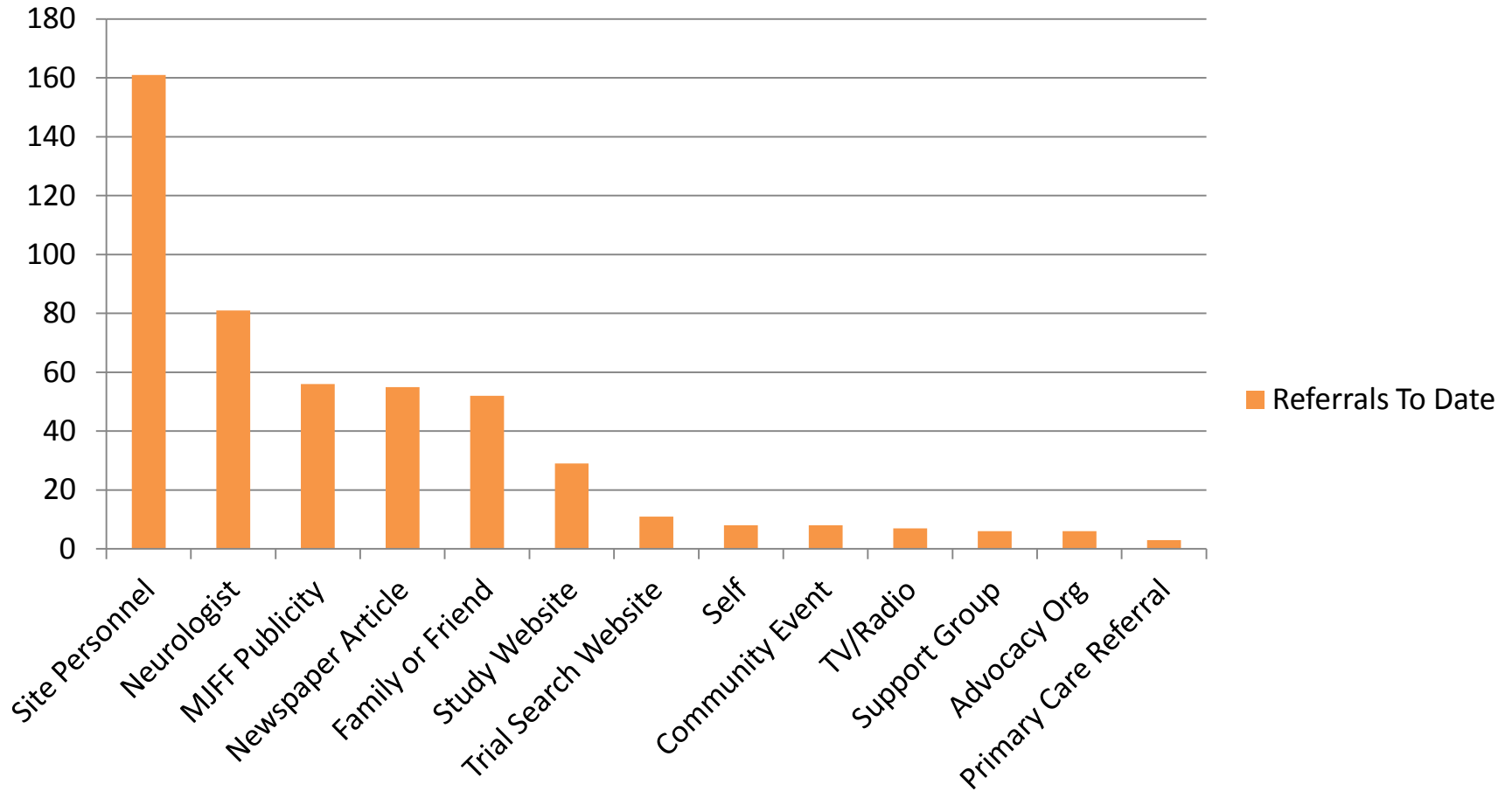
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# Recruitment Sources for Consented PD and SWEDD Participants



# 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



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# 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



# Retention progress to date

	<u>PD</u>	<u>Controls</u>	<u>SWEDDs</u>
% retained	99.0% (n=2 withdrawn)	98.6% (n=2 withdrawn)	96.0% (n=1 withdrawn)

- 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)



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# Site Awards

Drumroll, please.....



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# 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



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# Sites that met the year 1 goal in less than 12 months

- Tie for 3<sup>rd</sup> place:  
IND and OHSU  
Met Year 1 Goal in 11.5 months
- Tie for 2<sup>nd</sup> place:  
U South Florida and U Washington  
Met Year 1 Goal in 10.75 months
- 1<sup>st</sup> place:  
Cleveland Clinic  
Met Year 1 Goal in 9.75 months



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# 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....



# 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....



# 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?



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