

PPMI

Recruitment, Enrollment and Retention

Update to the PPMI Annual Meeting
May 5, 2011

Danna Jennings, R&R Working Group Chair



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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

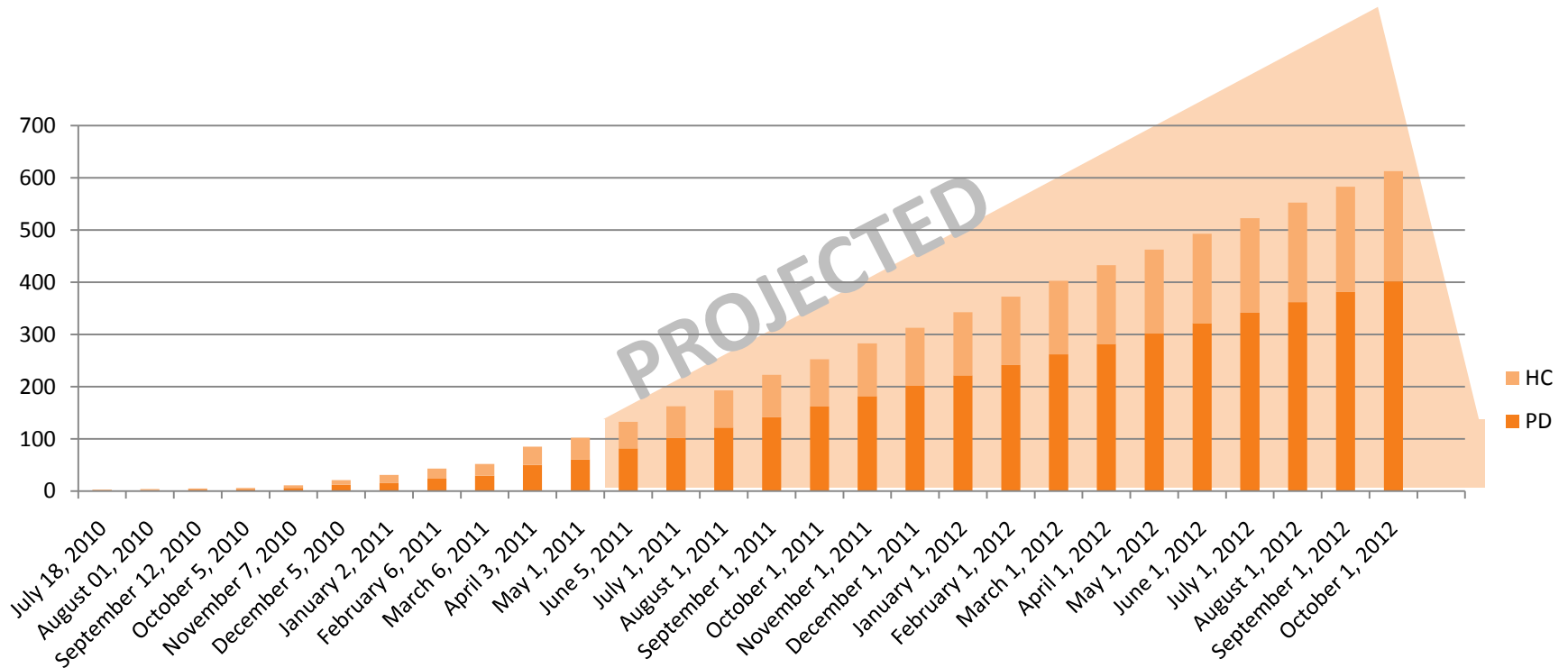


Revisiting our Recruitment and Retention Goals

- 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

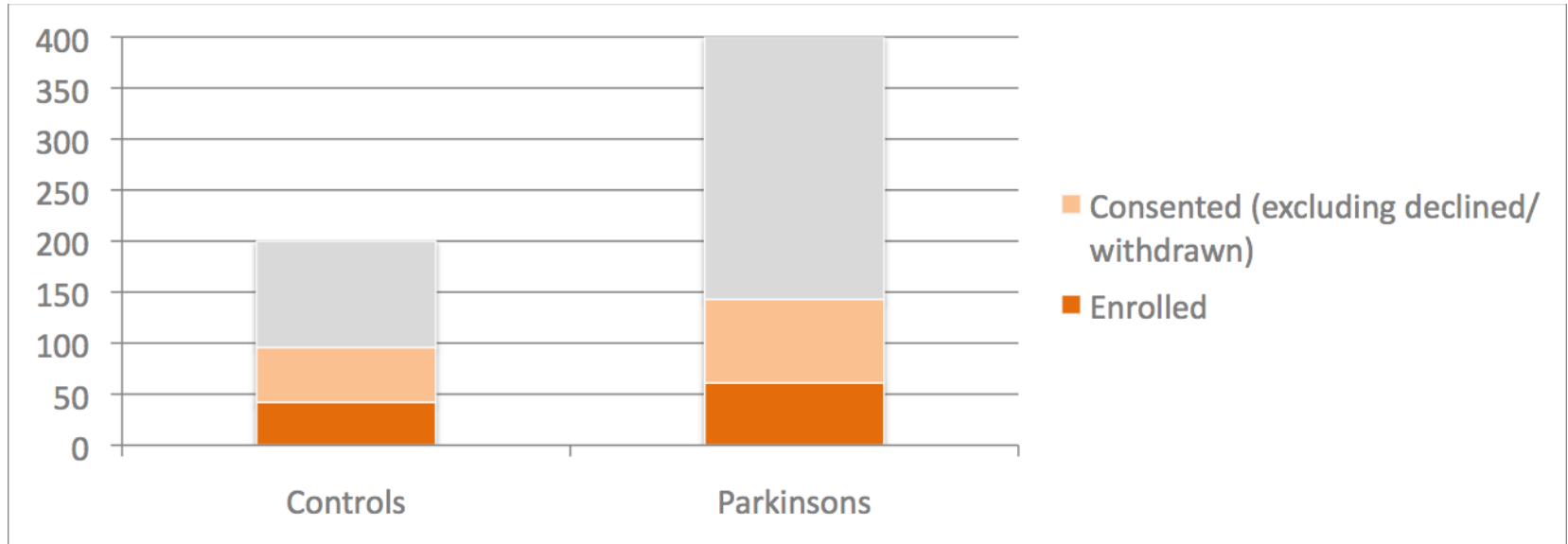


Recruitment and Enrollment in the next 17 months



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*)



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* Excluded/Declined/withdrawn subjects have been removed from these and all *consented* calculations throughout this presentation

Site Performance to Date - US

US Sites	Activation Status	Consented (excluding declined/ withdrawn)	Enrolled	
			PD	Controls
Baylor (Houston)	✓ Active	9	4	4
BU (Boston)	✓ Active	9	4	4
Cleveland Clinic (Cleveland)	Pending Activation (est April)	-	-	-
Emory (Atlanta)	✓ Active	11	3	6
IND (New Haven)	✓ Active	15	8	5
Hopkins (Baltimore)	✓ Active	3	0	2
Northwestern (Chicago)	✓ Active	13	5	2
OHSU (Portland)	✓ Active	15	9	3
The PI (Bay Area)	✓ Active	11	2	4
Sun Health (Phoenix)	✓ Active	4	3	1
UAB (Birmingham)	✓ Active	10	9	1
UCSD (San Diego)	Pending Activation (est April/May)	-	-	-
U Penn (Philadelphia)	✓ Active	7	2	3
U Rochester (Rochester)	✓ Active	6	3	2
U South FL (Tampa)	✓ Active	8	5	1
U Washington (Seattle)	✓ Active	10	3	1



Site Performance to Date - Europe

EU Sites	Activation Status	Consented (excluding declined/ withdrawn)	Enrolled	
			PD	Controls
Innsbruck U (Austria)	✓ Active	4	0	3
Paracelsus Klinik (Kassel/ Marburg Germany)	✓ Active	1	1	0
U Naples (Naples)	Pending Activation (est Summer)	-	-	-
U Tuebingen (Tuebingen)	✓ Active	1	0	0
Imperial College (London)	Pending Activation (est Fall)	-	-	-



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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



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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

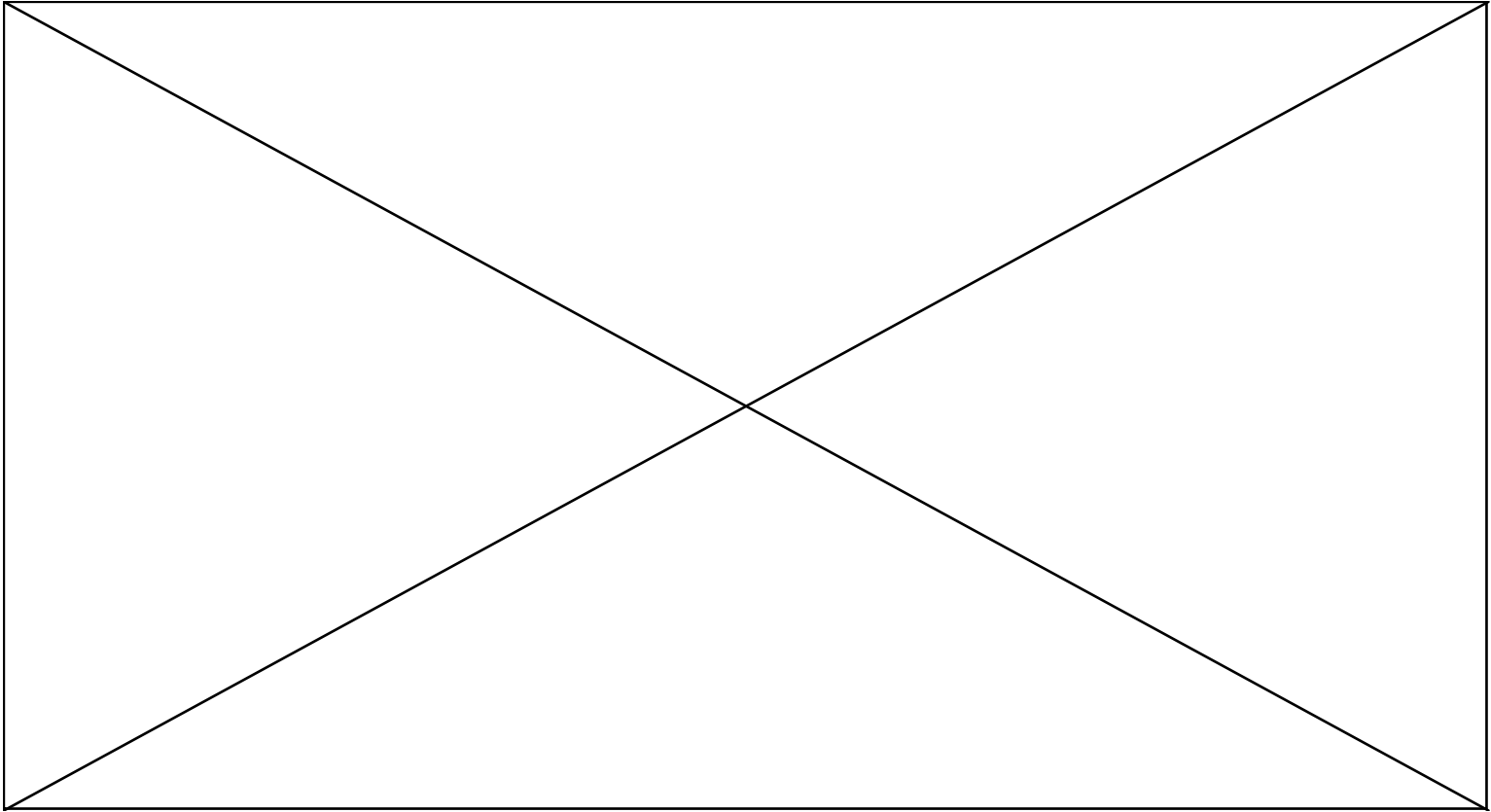


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PPMI Media Highlights Reel



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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



3.2%

3%

+ an additional 615 calls directly to site

237 people referred to site



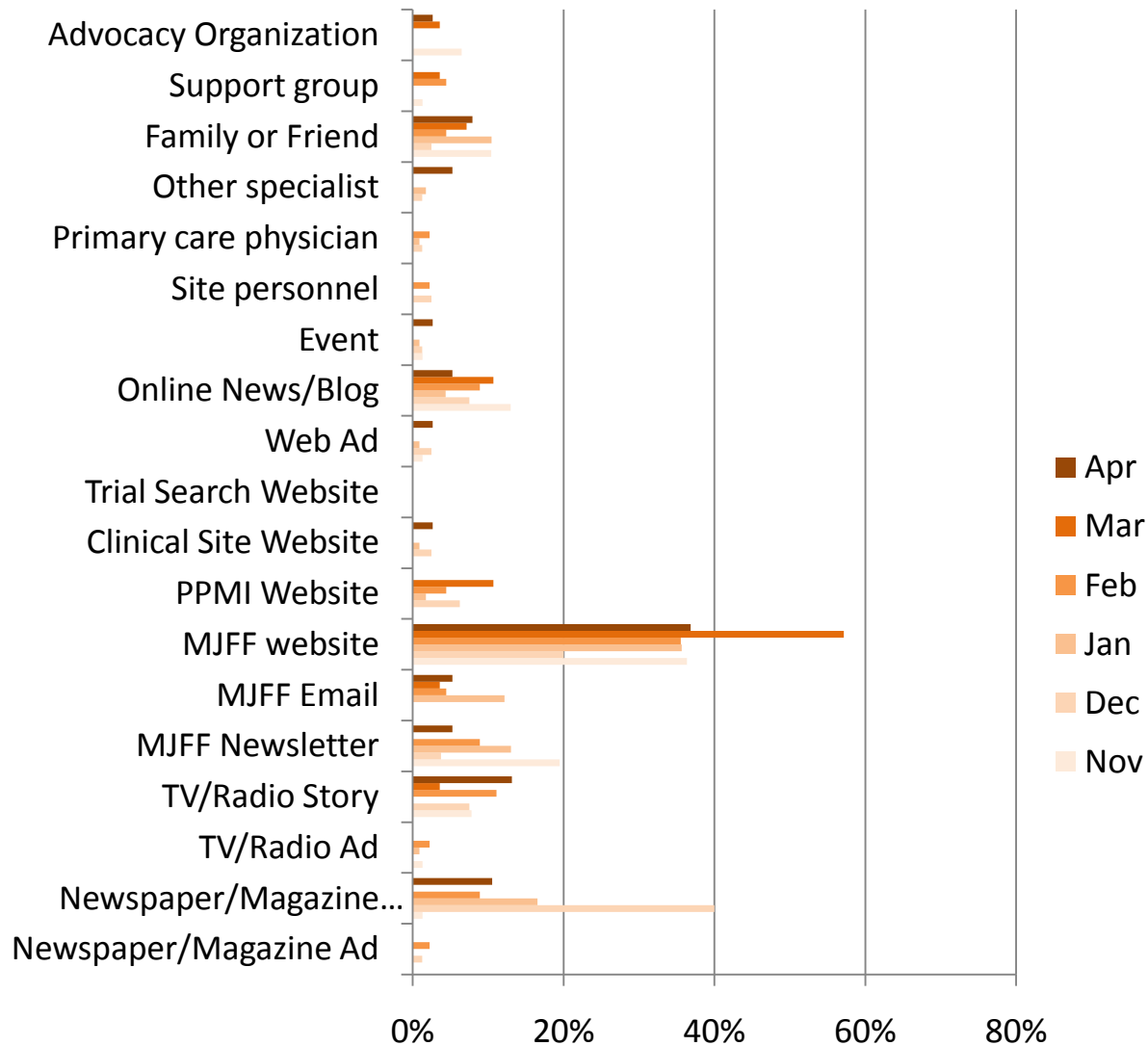
115 faxes have been returned
19 people (17%) have been screened
96 individuals not eligible or declined participation



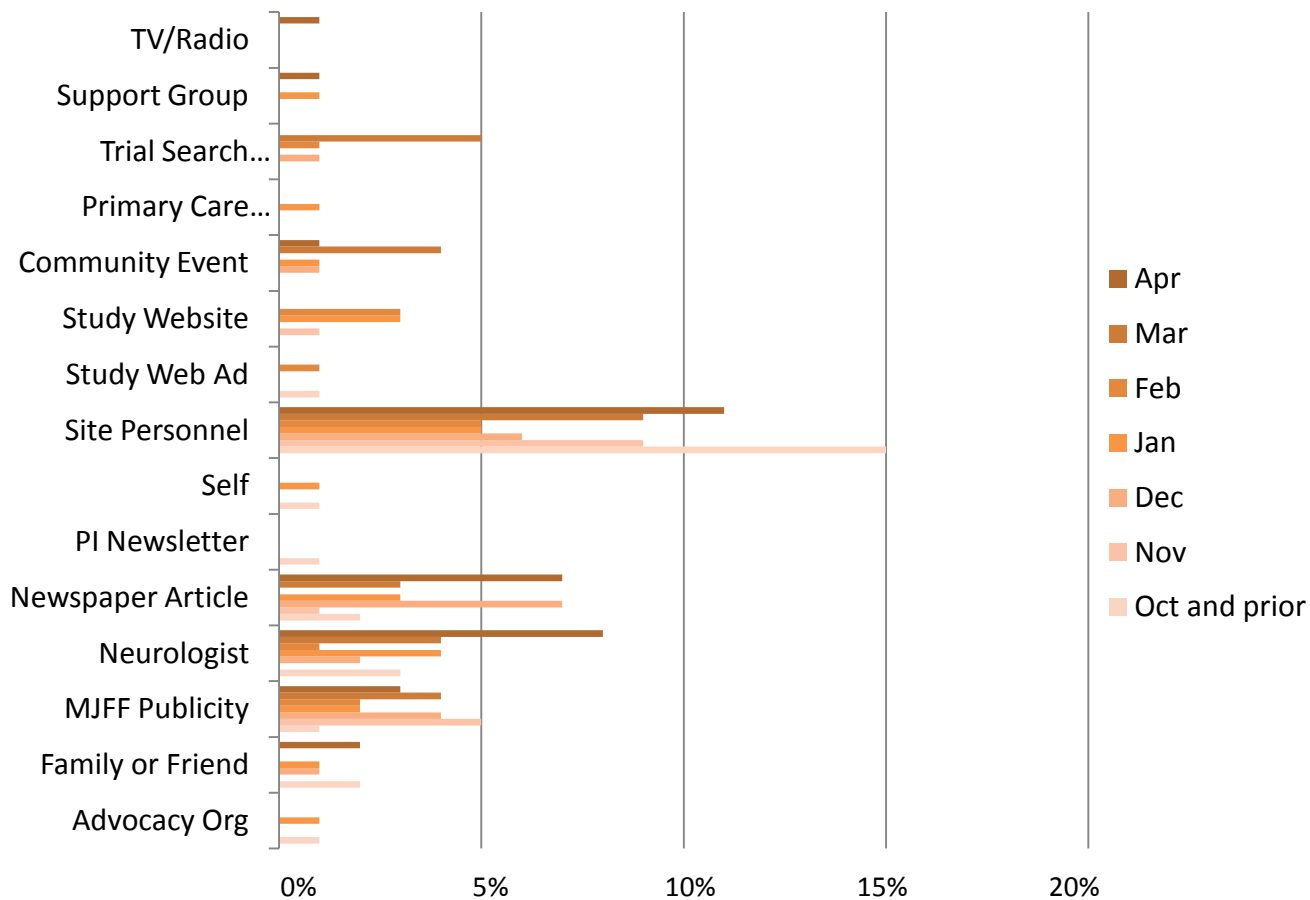
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Sources for Web and Call Center Inquiries



Recruitment Sources for Consented Participants



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



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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



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Most Subjects Consented per Month

- And the winner is....



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!



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Most PD Subjects Enrolled

- And the winner is....



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!



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Most Controls Enrolled

- And the winner is....



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



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Best Recruitment Start in Europe

- And the winner is....



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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



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Most Creative and Effective Outreach to Referring Practitioners

- And the winner is....



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....



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



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Best (multi-pronged) Community Outreach Plan

- And the winner is....



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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?



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