# Recruitment and Retention Panel Discussion: Taking Retention to the Next Level

**September 26, 2016**

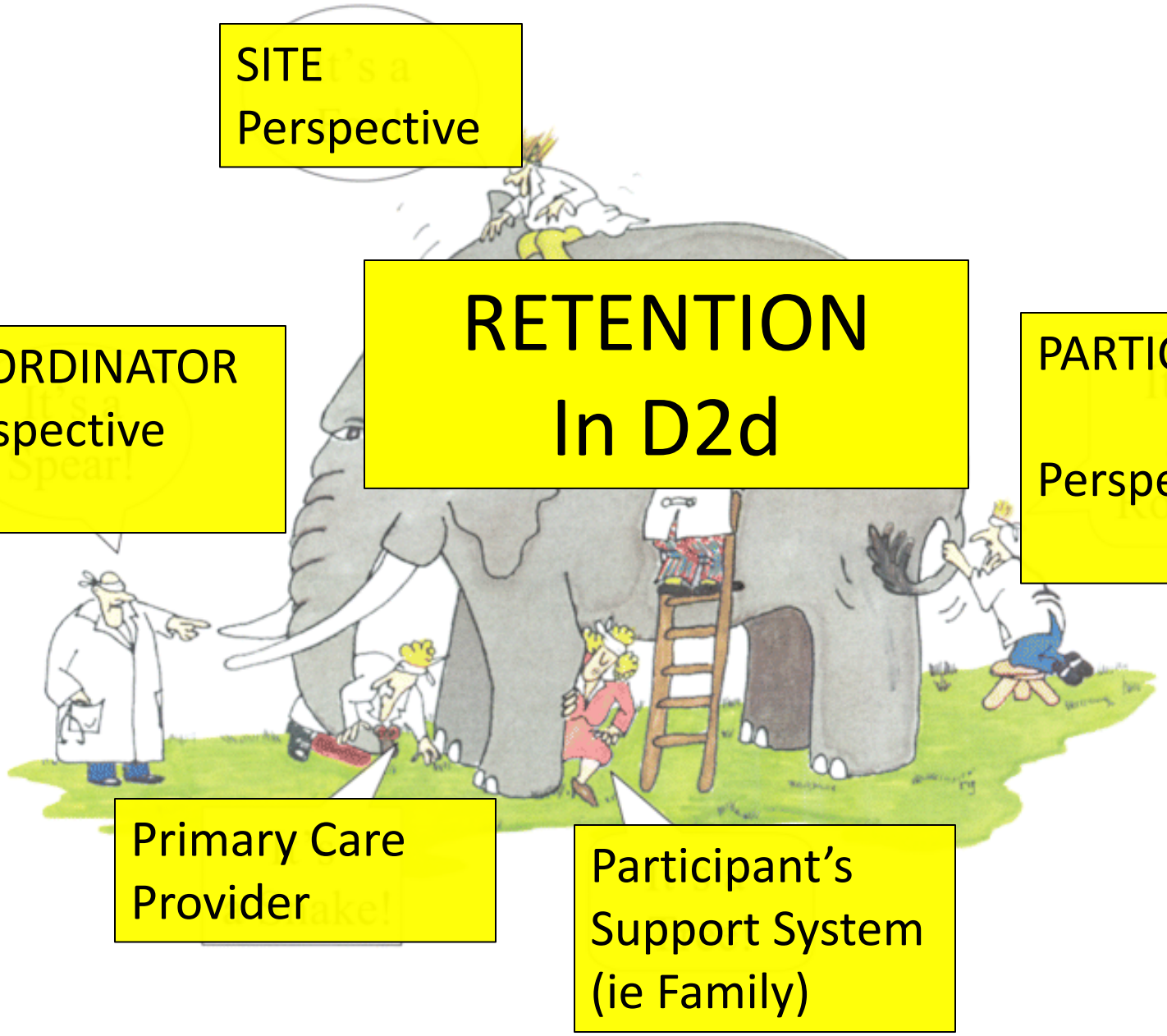
# Recruitment and Retention Subcommittee Membership

| Members | Site |
|---|---|
| Vanita Aroda (Chair) | MedStar Health Research Institute |
| Irwin Brodsky (Co-Chair) | Maine Medical Center Research Institute |
| Miranda Ouellette (Co-Chair) | University of Kansas Medical Center |
| Myrlene Staten | NIDDK |
| Chhavi Chadha | HealthPartners Research Foundation |
| Shelly Cook | HealthPartners Research Foundation |
| Erin Casey | Tufts Medical Center |
| Kim Vo | Tufts Medical Center |
| Sarah Serafin-Dokhan | Los Angeles Royal Comprehensive Health Center |
| Rincy Varughese | Atlanta VA Medical Center |
| Taso Pittas | Coordinating Center |
| Patty Sheehan | Coordinating Center |
| Cindy Haviet (CC Liaison) | Coordinating Center |

# RRS Panel Session Goals

- Provide examples of how your site can enhance retention.
- Provide suggestions on what makes a participant want to continue participating in the study and provide participant perspectives on what motivates them to remain in the study.
- Provide tools that coordinators can use to promote retention.

# Retention: The View


SITE
Perspective
RETENTION
In D2d
COORDINATOR
Perspective
PARTICIPANT
Perspective
Primary Care
Provider
Participant's
Support System
(ie Family)

# Q1: What are the best practices for retaining participants?

## Panelists

- Kaiser Permanente Center for Health Research: *Suzi Jones and Erin LeBlanc*
- Stanford University: *Melanie Rosenberg and Sun Kim*

# Retention efforts

## How to keep them coming back

Erin LeBlanc MD, PI & Suzi Jones RN, Clinic Coordinator

Center for Health Research Portland, Oregon

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# Best practices at Kaiser

- Pre-screening and subject selection
- Personal relationships
- Missed appointments

 

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# Identifying the long term participant

## Pre-screening

- Careful chart review for possible signs of future non-compliance
- Ease of reaching the participants initially by phone
- Red flags during recruitment telephone call

 

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# Participant A

- Newly retired, has free time
- Lives near the Research Clinic
- Has read the consent form and has written down a few questions
- Interested in making lifestyle changes and would like some advice

 

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# Participant B

- Difficult to reach by phone; does not return calls
- Complains about traffic and the inconvenience of the screening visit
- “I’m not good at taking pills”
- Has not read the consent or completed the medical history forms at screening visit

 

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# Fostering a positive attitude toward visits

## Personal relationships

- Friendly, knowledgeable study staff
- Personalized care
- Reducing the burden with reminder calls and flexible scheduling

 

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# Our study team

- Excellent interpersonal skills
  - good sense of humor
  - know the protocol and can answer questions
- Use scripted yet personalized telephone interactions
  - ensure participants receive thorough and accurate information
- Individualized chart notes
  - document important topics/people in the participant's life (travel, crises, triumphs & loss)
  - Review prior to and update during the visit.

 

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# No shows and No answers

## Missed appointments

- Develop a procedure of escalating attempts
- Be flexible
- Know when to say when

 

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# Sigh… What do we do now?

- Create standardized procedures
  - steps to take and clear documentation of efforts
  - Phone calls, hand written letters, phone call from the PI
  - Repeat as necessary
- Once reached, try to ascertain why
  - Offer a shortened or modified visit or just phone contact
- If they clearly do not wish to participate, respect their decision
  - no means no

 

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# Questions and comments?

# ENHANCING RETENTION

Sun Kim, MD and Melanie Rosenberg, BS

September 26, 2016

D2d Vitamin D and type 2 diabetes

diabetes prevention research matters

# Outline

- Not all study participants are created equal
- Why they become lost to follow-up
- How to fix it
- What's worked for us
- What's worked for you

# The Spectrum of Study Participants

- Retention efforts must be tailored to meet each individual's specific needs

**Actively Disengage** | **Not Engage** | **Somewhat Engaged** | **Highly Engaged**


**"I love medical research and OGTTs!"**

# Top 3 Reasons for Losing Interest

- **Not having expectations met**
  - Wants test results, upset about human error
- **Personal health**
  - Side effects, lab results outside of study
- **Life events**
  - Work, family, money

D2d Vitamin D and type 2 diabetes

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# How to Fix It

- Figure out the root cause
- Build a relationship
- Show that we care
- Persist
- Involve PI
- Take what we can get

D2d Vitamin D and type 2 diabetes

diabetes prevention research matters

# Case Example: Karl Kale

- **The situation:**
  - Going through a recent divorce.
  - Running a business and "too busy" for the study.
  - No-showed multiple visits, but still responsive to contact attempts.
- **The fix:**
  - Listened to his problems and showed that we cared.
  - Agreed to skip a visit and try again next time.
  - PI came to visit when he finally made it in.

D2d Vitamin D and type 2 diabetes

*diabetes prevention research matters*

# Case Example: Sally Sunshine

- **The situation:**
  - Recent A1c was 6.4% at annual PCP visit.
  - Considered dropping out of study to start Metformin.

- **The fix:**
  - Had a dietician meet with Ms. Sunshine at the Month 3 visit.
  - PI called to check in and answer questions. Also spoke with PCP.
  - Agreed to hold off on meds.

D2d Vitamin D and type 2 diabetes

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# What's Worked for You?

- **The situation:**
  - Participant has no-showed multiple visits.
  - He continually said he's very busy with work.
  - Now he is ignoring all contact attempts.

- **The fix:**
  - How would you solve this?

D2d Vitamin D and type 2 diabetes

*diabetes prevention research matters*

# Q2: What are innovative ideas to enhance participant engagement and build relationships?

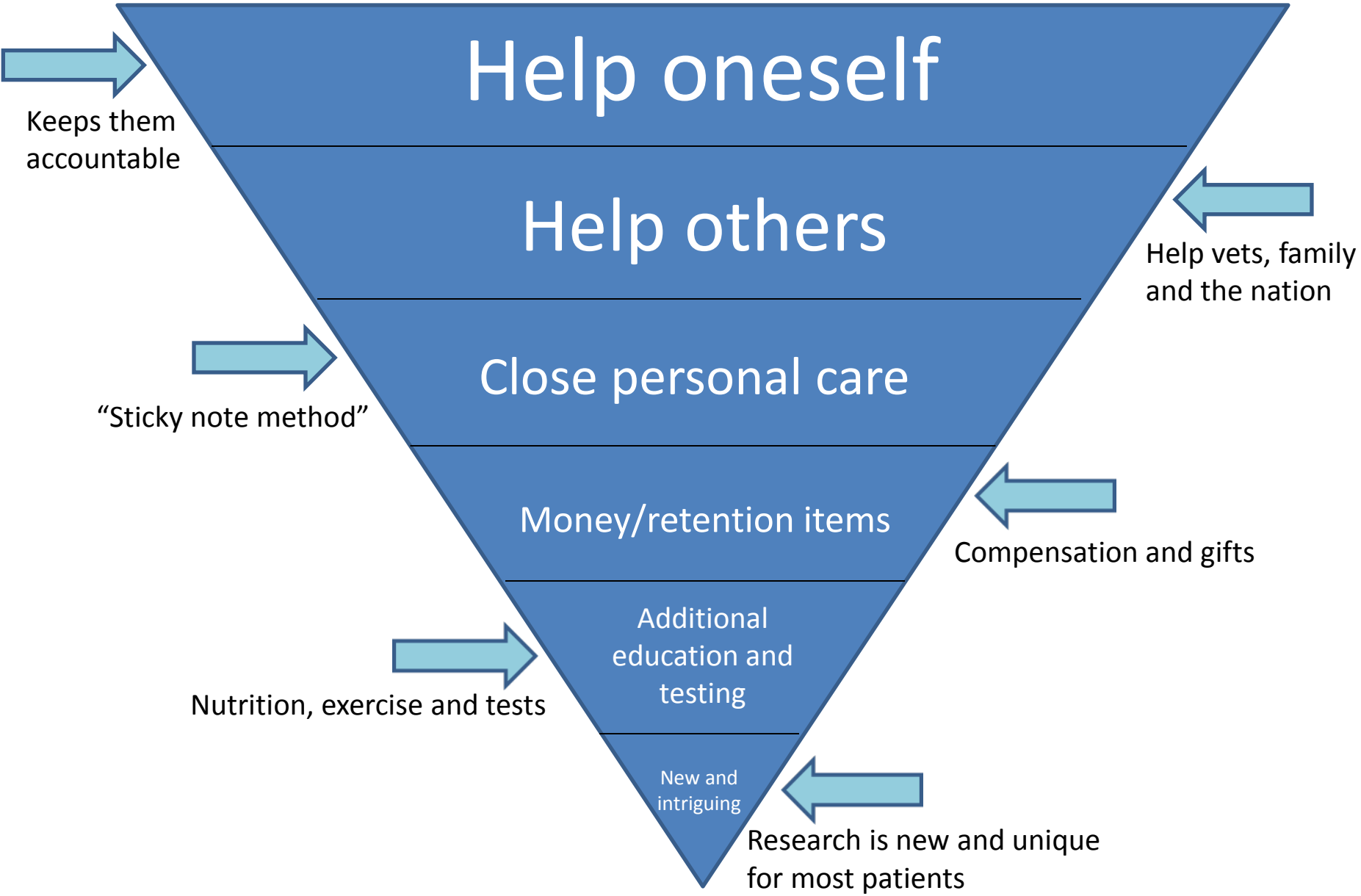
**Panelists:**

- Maine Medical Center: *Irwin Brodsky*
- University of Nebraska: *Jeff Newcomb and Tara Asgarpoor*

# Hear from a volunteer

- "i am not involved in this study because of the nice little mugs, etc. I am involved mainly to try to improve my own health and, in some small way, to help advance medical knowledge. Programs that include information about the latest research and suggestions to improve one's health--especially to avoid developing diabetes are what I would most appreciate. However, programs during the day do not work for me--early evening times are more possible. Thanks!" –PV
- "Hi Dr. Brodsky, Unfortunately, I live too far to take advantage of some of your social and educational events. The small gifts are nice and fun to receive, but not always necessary. (I would never use a T-shirt as I don't usually wear those! ☺). I participate because I want to do anything I can to help end Diabetes. I also hope that by participating, it will remind me to improve my own lifestyle and focus on prevention. Thanks for checking in! Hard to believe it has been 2 years already. Thanks very much,"—CD
- "Hi! I think Jacki and Lori are the best part of the study! Always fun to talk to! They are so encouraging! Would be interested to know what the research article in Norway said...maybe a mini-condensed e mail version? Thanks for keeping in touch!" – CP
- "I have enjoyed being part of the D2d study especially working with Lori and Jackie. They make me feel like I'm part of the family! I prefer to attend lunch and learn activities as a gentle reminder to continue good behavior."--CT


# Foundation Blocks of Retention



# Q3: What retention methodologies have you used and do they work?

**Panelists:**

- Tufts Medical Center: *Erin Casey and Kim Vo*
- MedStar Health Research: *Theresa Young and other MedStar team member*

# While in D2d

Tufts Medical Center

**Before Screen**
- Detect potential "trouble", and reject at pre-screen (preferably) or screening visit

**Before Visit**
- Friday before: call and email (mail or text) confirmation
- Day before: call, email, or text reminder

**During Visit**
- Comfortable and welcoming research environment
- Write personal note in binder about participant to build relationship
- Appointment card (contact info, participant reminders, next scheduled visit) and email confirmation of next scheduled visit
- PI meets with participant at M24 visit

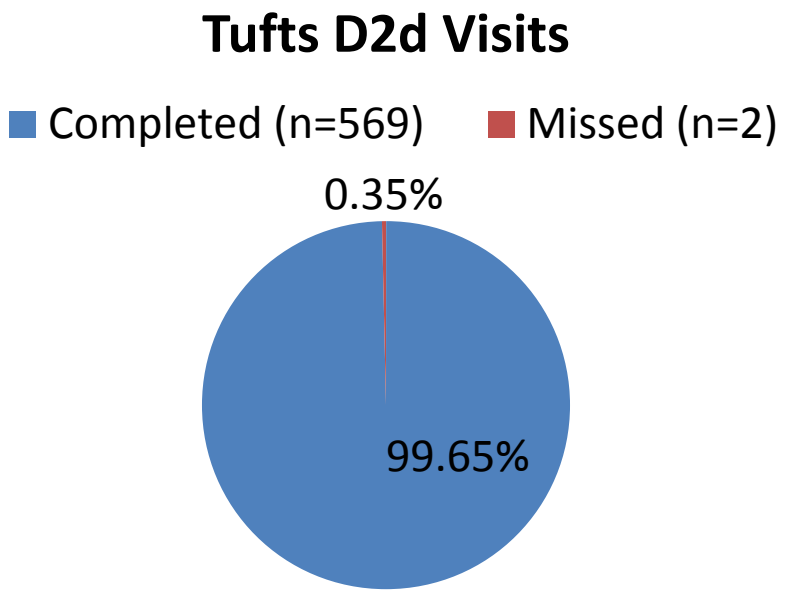
**After Visit**
- Email or mail results to participant
- Mail results to participant's PCP
- Send PI hand-written card with mention of personal note by coordinator

**Between Visit**
- Mid-visit follow-up email with protocol questions and date of next scheduled visit
- Mid-visit follow-up phone call to "issue" participants
- Holiday and birthday cards

**Weekly Meeting**
- Ellen's weekly report
- Discuss "issue" participants: progress and action plan
- Tiger Dad

# Bottom Line:

- Establish relationship early
- Participant sees value in participation



MedStar Health Research Institute

Knowledge and Compassion
**Focused on You**

# D2d Study

## Retention Methodologies

*The Clinical Research Coordinator's perspective*

Veronica Rodriguez, Clinical Research Coordinator
Theresa Young, Clinical Research Coordinator

# Weekly Tracking

| Total current | Total active | Protocol visit status | Outstanding visits |
|---|---|---|---|
| Current | Active | Completed % | Scheduled |
| 145 | 150 | 96.7% | 0 |

# Retention Strategy: The 5-Week Recovery Plan

- **When to implement the plan:**
  - Missed visits
  - Not willing to commit
  - Unable to reach patients

# 5-Week Recovery Plan

- ✓ **Weeks 1-2:**
  - ✓ Coordinator calls and email participant
- ✓ **Week 3:**
  - ✓ Participant is contacted by an Investigator
- ✓ **Week 4:**
  - ✓ Send certified letter. Give patient 2 weeks to accept letter.

## We missed you note

Site PIs

date

Dear _____,

We hope everything is going well. We want to remind you that visits to meet with the team are a *very important part of helping you to manage your pre-diabetes*. In addition to giving you important health information, these visits are **vital** to the research aspect of D2d. The knowledge gained from the D2d study will influence the future of diabetes prevention and provide the medical community with information needed to better prevent this common disease.

Because D2d is a research study, it is very important for us to get your health information. You are irreplaceable to us. Also, remember that we will keep your physician informed by providing him or her with your blood pressure, blood glucose and other lab values.

Please call _____or _____ to set up an appointment for your follow-up visit. We will try to work around your schedule. Or just give us a call to touch base and we can figure out a time for a visit at a later time.

We realize you are busy, and in appreciation for your time, we will provide you with a stipend upon your next in office visit.

We look forward to hearing from you.

Sincerely,

Coordinator info.

# Post-Plan Activities

- If still no contact or no response from letter, start calling emergency contact
- Check EMR to see if participant has an upcoming visit with PCP.
- Give a slight break from attempts, then reach back out on personal or different cell phones
- ***NEW* - "Adele Letter" to be mailed**
- ***NEW* - Follow-up to Adele**

# "Adele" Letter


"We would like to remind you that it is important for individuals with pre-diabetes to have their sugar levels tested once a year to ensure that they have not progressed to the diabetes range. This can be done by your PCP or D2d Team."

MedStar Health Research Institute

Hello_____,

We hope you are doing well. It seems that something has prevented you from attending D2d study visits and/or keeping in touch with us. As you recall, this is a study evaluating whether vitamin D can prevent diabetes. We would like to offer you the following options that we hope will work for you.

1) **Come to the Good Health Center once a year FASTING for bloodwork (10-15mins) to monitor your blood glucose and Hemoglobin A1c.**
   **This can be unscheduled, at your convenience (Mon-Fri 7am-3pm), please call us to confirm a time outside of this window if desired.**

   ***Eligible to receive $50 stipend***

2) **Answer the following questions once a year:**

   a. **Have you been diagnosed with Diabetes?**

   b. **Are you taking the study pills?**

      **If so, are you willing to receive new bottle in person or by mail to continue.**

   c. **Are you taking any vitamins or supplements that contain Vitamin D and/or Calcium?**

      **If so, how much total Vitamin D? Total Calcium?**

Please respond to us by phone, mail or email with your decision:

| Mailing Address | |
|---|---|
| Coordinator Contact Info | Coordinator Contact Info |

REMINDER

We would like to remind you that it is important for individuals with pre-diabetes to have their sugar levels tested once a year to ensure that they have not progressed to the diabetes range. This can be done by your Primary Care Physician or D2d team.

**We value your opinion please let us know if there is anything we can do differently to reconnect with you.**

Thanks for making D2d possible

D2d Vitamin D and type 2 diabetes

"We value your opinion please let us know if there is anything we can do differently to reconnect with you."

# Follow-Up to “Adele”

MedStar Health Research Institute

**Dear Mr./Ms._____,**

As mentioned in our last letter, please answer the following questions and return back by the pre-stamped envelope included. Our endocrinologists are available to answer questions/concerns about your health.

| | |
|---|---|
| **Have you been diagnosed with Diabetes?** | ☐ YES<br>☐ NO |
| **Are you taking the study pills?** | ☐ YES<br>☐ NO |
| **If Yes, are you willing to receive a new bottle in person or by mail to continue?** | ☐ YES<br>☐ NO |
| **Are you taking any vitamins or supplements that contain Vitamin D and/or Calcium?** | ☐ YES<br>☐ NO |
| **If Yes, What is the total dose of each per day?** | **Total Vitamin D** _____ **IU**<br>**Total Calcium** _____**Mg** |

| Mailing Address | |
|---|---|
| Coordinator Contact Info | Coordinator Contact Info |

**REMINDER**

We would like to remind you that it is important for individuals with pre-diabetes to have their blood sugar levels tested once a year to ensure that they have not progressed to the diabetes range. This can be done by your Primary Care Physician or D2d team.

**We value your opinion! Please let us know if there is anything we can do differently to reconnect with you.**

Thanks for making D2d possible

D2d Vitamin D and type 2 diabetes

**“Are you willing to receive study pills in person or by mail to continue?”**

# Tracking Tips

- Hold a weekly (~30 minutes or less) meeting to track retention risks
- Keep a running log of all previous attempts
- Each week brainstorm new strategies and give assignments for the week

| A | B | C | D | E | F |
|---|---|---|---|---|---|
| Subject ID | Encounter | Target Date | Status | Plan | Comments |
| | M09 / M12 | 2/25/2016 - 5/26 | multiple early no shows with Zayd, texted back and forth with Z but then # disconnected, cert letter sent & signed for. Zayd LVM with ER contact and then Dr. Park LVM with ER contact 4/7/16 | 1. keep trying phone #, Theresa send letter<br>2. no luck with # as off Thurs. 4/21<br>3. handwritten letter remailed 4/21, wait one week<br>4. Zayd to call from a "weird #" - no answer<br>5. Discuss on Wed - Dr. Park or Ghazi to reach out to new PCP at prompt care<br>6. Dr. Park is trying once more, has all contact info possible.<br>7. New number listed on Promptcare contact form 410.243.7322 (T LVM on landline 6/13/16)<br>8. Dr. Aroda (called and LM 7/19/16)<br>9. Adele letter mailed with first aid kit in large envelope 8/11/16 | Follow-up after labor day... then send F/U to Adele |
| | M18 | 6/1/2016 | | 1. spoke to her, she will call back with schedule. 5/16 TY<br>2. no answer, no machine 5/24/16<br>3. Dr. Park to call<br>4. hung up on Dr. Park x2<br>5. T- LVM 6/13<br>6. Saif LVM 6/20<br>7. T - sent letter 6/20<br>8. Theresa called ER contact 6/30 spoke to participant's Mother. Edna Snead. Stated everything was fine. I asked that she please let her know we were trying to reach her and to have her give us a call. I mentioned she was folllowing-up regularly with the study and then recently we have had trouble reaching her.<br>9. Saif LVM 7/8/16.<br>10. Dr. Park- 7/14 I left a message for Earthell Keys- briefly leaving a message similar to what I told Ronette Goodwin. I also called Ms. Snead, her daughter (who is the study patient's sister) said she is fine, so I relayed that I left a message for Earthell.<br>11. Letter mailed with D2d "goodies" (pedometer and first aid kit) 7/19/16.<br>12. Theresa LVM 8/1/16<br>13. Dr. Aroda LVM for Ms. Keys 8/9/16 | phone call after labor day and if no response, LVM that we will be sending the Adele letter ... |
| | M06 | 6/18/2016 | | 1. "The firefighter guy" plan is to call him end of July or early August. We did a non-contact visit for M3 after talking to Paul.<br>2. Theresa LVM 8/1/16<br>3. Dr. Ghazi tried but did not LVM yet, will try again. 8/10/16<br>4. Dr. Ghazi called on Wed or Thurs last week (8/24 or 8/25) and he hung up on her. | Text message with options? |

# Missed Appointment Note

Re: Participation in the Vitamin D and Type 2 Diabetes Study (D2d)

date

Dear _____,

We are writing because you missed your D2d study follow-up appointment and we have not been able to contact you. We are concerned because we need to carefully monitor your health during the study.

Please contact us as soon as possible to update us on your status and schedule a follow-up appointment. You can call the study coordinator, Coordinator at ###-###-#### or you can email her at EMAIL. We will work with you to find a time that is convenient for you.

We appreciate your continued participation in the study and thank you for your time. We look forward to seeing you.

Sincerely,

Contact Info.

# PI Letter

Vanita Aroda, MD
MedStar Health Research Institute
6525 Belcrest Rd. Suite 700
Hyattsville, MD 20782
Phone: 301.560.2915
Fax: 301.560.2948

Date

Dear _____,

I hope this letter find you doing well! It has been some time since we have heard from you, but we still very much want to help you manage your pre-diabetes and provide you with ongoing education and support in any way we can through the D2d study. I know you are kept busy and we completely understand that there are other obligations that may come first for you. Nonetheless, we are here for you and can work out a schedule for your visits that is convenient for you, however often you are willing to come in. We would like to know your interest and intent as far as continuing with D2d. We are flexible and can work an alternative schedule that may be more convenient for you.

Because D2d is a research study, it is very important for us to get your health information. You are irreplaceable to us. Also, remember that we will keep your physician informed by providing him or her with your blood pressure, and other lab values. In addition, the knowledge gained from the D2d study will influence the future of pre-diabetes treatment and provide the medical community with information needed to better understand this common disease.

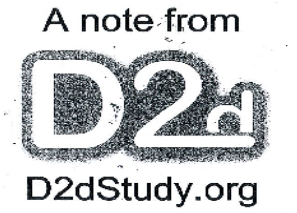
Please call _____ at ###### or _____ at ##### to discuss options for your continued participation. We truly appreciate all your time and effort up to this point, and are committed to working with you in any way you prefer.

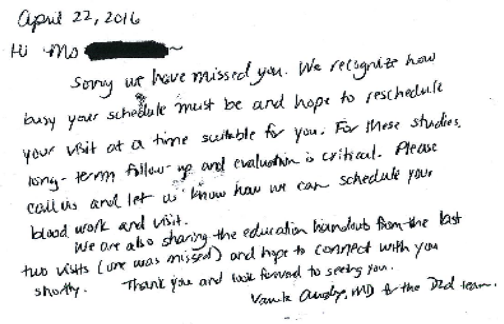
We look forward to hearing from you!

Sincerely,

Vanita Aroda, MD

# Handwritten Note / Birthday cards





April 22, 2016

Hi Mr [redacted]

Sorry we have missed you. We recognize how busy your schedule must be and hope to reschedule your visit at a time suitable for you. For these studies, long-term follow-up and evaluation is critical. Please call us and let us know how we can schedule your blood work and visit.

We are also sharing the education handouts from the last two visits (one was missed) and hope to connect with you shortly. Thank you and look forward to seeing you.

Vanik Saukya, MD & the D2d team.


# Case 39

- Subject currently at Month 30
- Patient got a new job at M24
- Patient angry when called by site staff , missed visit
- At M27 pt. decided to withdraw. CRC offered non-contact visit, pt. agrees.
- At M30 non-contact visit CRC provides optional in person visit, pt. agrees
- M30 completed
- Patient back on schedule

# Case 104

- Subject Randomized on 7/25/14.
- Currently at M24
- Has not had an in person visit since his randomization.
- Some visits have been completed via phone.
- Patient currently unresponsive to calls, emails, certified letter. Follow-up/ checklist letter sent 9/12/16
- Patient unresponsive to site P.I. calls, emails and handwritten note.


# Case 55

- Subject randomized 6/4/15, currently complete at M15
- Patient was unresponsive after M3
- When she was reached, she would not commit to an appointment. Eventually cell was out of service.
- Site PI attempts made.
- Certified letter sent in Feb. 2016 was accepted and cell number was back on.
- Scheduled M6 (3 months out of window).
- Subject had changes in work schedule and personal priorities that were competing.  Has since been in communication and up to date on all visits.

# Case 05


- Subject Randomized 12/1/14
- Participant has been unresponsive since trying to schedule M18.
- Coordinators were waiting for a call back after a brief conversation to schedule.
- Multiple attempts by coordinators and Site PIs.
- “We missed you note” sent certified, no response.
- PI connected with ER contact and was told “everything is fine.” Once again reached out to participant with no response.
- Another letter mailed with D2d give-a-ways.
- Dr. Aroda LVM
- Adele letter is the next step.