



**Stanford**  
M E D I C I N E

# Operation Housecall

Collaboration between the Stanford MS Program in Human Genetics and Genetic Counseling and the Silicon Valley Down Syndrome Network

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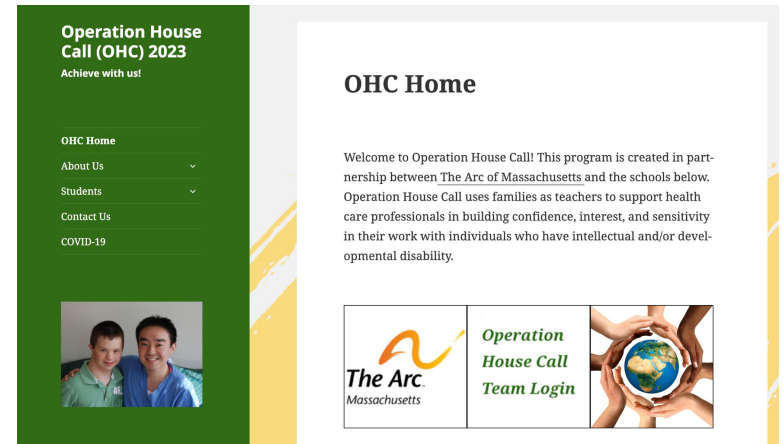
# What Is Operation Housecall?

Began in 1990's in Boston: Boston University and The ARC of Massachusetts

Student in degree program paired with a self-advocate



SVDSN Graduation Picnic, May 2022



The Arc of Massachusetts Operation Housecall website

# Operation Housecall at Stanford

Collaboration between Human Genetics and Genetic Counseling  
Master's degree program and SVDSN

Pairs first-year genetic counseling student with SVDSN family

- April 2009: Initiated discussion with Kelly Ormond, faculty director
- Fall of 2009: matched SVDSN families with first- and second-year students
- Fall of 2020: pivoted to virtual meetings
- Fall of 2023: pairing our 15th cohort

# Operation Housecall Goals

## Student

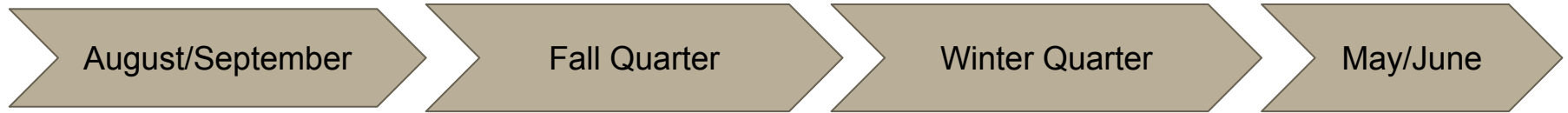
- Provide an opportunity to ask questions in a non-clinical setting
- Give students parent- and self-advocate-perspective insights
- Provide students with parent-perspective information (in person and books)

## Family

- Provide a judgement-free space for families to share about their own experience in receiving a diagnosis of Down syndrome
- Empower families to support others following on this path
- Encourage families to engage and volunteer with SVDSN

# Program Overview

## Operation Housecall Program Timeline



- SVDSN Families are recruited
- First-year students arrive on campus
- Family/Student pairs are matched

- Families arrange meetings with students
- Students are invited to attend the BuddyWalk

- Students meet to reflect on and share experiences
- Students have one class with pair of parent speakers
- Students receive *Raising Henry* book

- Graduation Picnic
- Students receive *Gifts* and *Gifts II* books

# Books for Students

- *Raising Henry* by Rachel Adams
- *Gifts: Mothers Reflect on How Children with Down Syndrome Enrich Their Lives*, ed. Kathryn Lynard Soper
- *Gifts II: How People with Down Syndrome Enrich the World*, ed. Kathryn Lynard Soper



OH Graduation Picnic 2011

# Family Expectations and Timeline

Families volunteer in September- complete questionnaire

## Expectations:

- Fall Quarter: Meet one time with their first-year student for at least one hour
  - During pandemic: pivoted to Zoom/virtual meeting with a pair of students
  - Now: either by Zoom or in-person meeting
- Families are given flexibility to arrange meeting with their student
- Meeting may occur in family home or in the community
- Families encouraged to invite their student to participate in the BuddyWalk
- May/June: participate in graduation picnic

# Student Expectations and Timeline

## What?

- (description of the program's history)

## So what?

- This interaction is an opportunity for parents to share their experiences and for students to ask questions to gain a better understanding of both the joys and challenges that families in this situation encounter. The goal of the program is to educate students about the lives and medical needs of children and adults with developmental disabilities and the unique barriers they face in accessing medical care.

## Now what?

- We will pair you with a family. In some cases, there will be multiple students paired with the same family. You will contact your family to determine a convenient time and place for your visit (in person or Zoom), during which they will try to provide a holistic sense of their experience. They will do so by sharing their stories of challenge and success, as well as pieces of their everyday life. They may talk about social issues, educational issues, family dynamics, interactions with healthcare providers, etc. You are expected to ask questions, listen and learn, but not provide care or genetic counseling. Our hope is that you will fit into the everyday routine of the family and household, which may involve watching the parents provide care, daily activities, and possibly playtime. The goal of the experience is to become more aware and sensitive and to develop improved communication skills with families. This may involve a single visit or a longer relationship, at the discretion of both parties. **Be prepared to discuss your experience during class.**



# Getting Started

Identify one individual from each organization to manage communications w students and families

Administrative support:

- Fall:
  - administer family questionnaire;
  - match pairs
- Winter:
  - order books
- Spring: reserve picnic space,
  - send invitation/collect rsvp's
  - arrange lunch catering, etc.



OH Graduation Picnic 2023: SVDSN Taiko

# Recruiting Families

## # of volunteer families with age ranges of the self-advocates:

- 2018: 17 families, 2-21yo
- 2019: 13 families, 3-25yo
- 2020: 11 families, 3-24yo
- 2021: 12 families, 6-23yo
- 2022: 27 families, 1-27yo

**Matched with 11 -> 15 students**



2023 OHC Picnic

# The Student Experience

Operation Housecall deepened my appreciation for the resilience of families, and I learned ways to deliver challenging information empathetically and equitably. - *Evan*

I had such a lovely time with my Operation House Call family! Prior to the experience I had never met anyone with Down Syndrome and it was a great opportunity for me to learn from the family and give them the space to share their experiences with the medical system. They were so passionate about helping the community by educating future healthcare providers, and it is already a highlight of my graduate education. My family and I got along so well and they even sent me a holiday card last year. - *Olivia*

"I am so grateful to the family I was paired with during Operation House Call for their enthusiasm and eagerness to share their experiences with a fresh GC trainee. Also, the Operation House Call picnic at the end of the year was SO special and memorable! - *Kayla*

# The Student Experience

When I first met my family, they invited me to their house, we played games together, and told stories of our struggles and joys. *Tres*, who has down syndrome, is the middle child in their family. *Tres* has a silly sense of humor and a contagious laugh. His relationships with his younger brother, older sister, and parents are fun and incredibly loving... we couldn't stop laughing. I had only met *Tres'* family for the first time that day. Still, they welcomed me to share in their everyday moments of happiness and gratefulness. Along with a range of other emotions like the inevitable moments of sibling bickering and exhaustion from an entire day of responsibilities. It all felt like home. Operation House Call is about finding a sense of home in each other and learning how to build a home in others.

- *Michelle*

Operation House Call was an invaluable opportunity that enriched me both professionally and personally. Connecting with this remarkable family allowed me to witness their joys and gain key insights into the unique challenges they face. It highlighted the need for informed healthcare professionals, greater societal inclusion, and improvement in continuity of care as their children transition into adulthood. This experience reaffirmed my commitment to seeing the person behind the diagnosis and has forever shaped my perspective as a future genetic counselor. - *Lizzy*

# The Student Experience

I had a case today where I was able to spend an hour and a half with a couple discussing T21 and answering questions. I've had many T21 cases but this couple is the first to ask a lot of questions about the day to day/entire lifespan. I think about this with every T21 case, but the whole time I was thinking of my Operation House Call family and the resources/things they shared with me that have been the most helpful. I feel so lucky to know their story and to have that in the back of my mind! I wanted to text you and thank you for that opportunity and also share how much it's helping me! - *Callan (alum)*

# Operation Housecall Online Resources/Articles

<https://www.operationhousecall.com/about/>

Program at UCSD:

<https://journals.sagepub.com/doi/10.1177/0009922809332688>



**Any questions? Feel free to reach out:**

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