Raising Awareness. Funding Research.
Supporting Patients. Achieving the DREAM!

www.DebbiesDream.org
Welcome to today’s webinar on Clinical Updates - Genomic Research Studies in Gastric Cancer
Dr. Adam Bass
Andrea P. Eidelman, Esq  
Executive Director

- Bachelors degree in psychology from the University of Miami
- Juris Doctor from St. Thomas University School of Law
- Spent most of her legal career advocating for the rights of underprivileged populations, specifically foster care children
- Oversaw the Jacksonville Area Legal Aid program and led Permanency Project at Legal Aid Services of Broward
- Worked as case manager for Health and Rehabilitative Services in Miami-Dade County assisting terminally ill HIV/AIDS patients
- Served on the board of the American Lung Association and Bella’s Kinship Group
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Be well
I. Introduction
   Moderator: Andrea P. Eidelman, Esq.

II. Debbie’s Dream Foundation: Curing Stomach Cancer

III. Clinical Updates - Genomic Research Studies in Gastric Cancer
   Presenter: Adam Bass, MD

IV. Questions and Answers
Stomach Cancer Facts

- In 2018, it is estimated more than 26,000 Americans will be diagnosed with stomach cancer each year, and more than 11,000 will die from the disease.
- Many patients are asymptomatic during the early stages of stomach cancer, leading to late diagnosis.
- At Stage 4, the 5-year survival rate is 5%.
- Overall 5-year survival rate is 30%.
- Incidence rates of stomach cancer in whites aged 25-39 increased by 66% between 1977-2006. This data is significant because the expected frequency of stomach cancer overall has declined over the past 80 years in the United States.
- Most people know very little about this deadly disease.
Debbie Zelman
Founder, Debbie’s Dream Foundation: Curing Stomach Cancer

- Diagnosed with stage IV stomach cancer in April 2008
- 40 years old, mother of 3 young children, married to a physician, and a practicing attorney with her own firm
- No risk factors for stomach cancer and symptoms were very vague
- Chance of being alive in five years was 4%
- Faced many recurrences and treatments over 9 ½ years
- April 2009 – founded Debbie’s Dream Foundation: Curing Stomach Cancer (DDF)
- Member of Deadliest Cancers Coalition, PEAC, SPEAC, OVAC
- Patient Advocate:
  - NCI Esophagogastric Task Force
  - NCI Patient Advocacy Steering Committee
  - NCCN Gastric and Esophageal Guidelines Committee
  - CDMRP DoD PRCRP Programmatic Review Panel
  - ASCO Gastric Cancer HER2 Testing Guidelines Project
  - American Cancer Society Research Program Stakeholder
Debbie’s Dream Foundation: Curing Stomach Cancer

Our Mission

DDF is a 501(c)(3) non-profit organization dedicated to raising awareness about stomach cancer; advancing funding for research; and providing education and support internationally to patients, families, and caregivers. DDF seeks as its ultimate goal to make the cure for stomach cancer a reality.

www.DebbiesDream.org
Debbie’s Dream Foundation: Curing Stomach Cancer

Milestones

- 29 Chapters in the United States, Canada, and Germany
- Events across the United States and Canada
- Patient Resource Education Program (PREP) - helps hundreds of patients, families, and caregivers throughout the world matching inquirers with stomach cancer survivors and caregivers using specific disease criteria
- Stomach Cancer Education Symposia and Webinars
- Website containing in-depth stomach cancer information, lecture library, clinical trial information and matching service, stomach cancer support community, blog topics, and resources which are completely translatable into more than 60 languages
- $950,000 in Research Grant Funding
- Stomach Cancer Capitol Hill Advocacy Day and Capitol Hill Briefing
- $50 million DoD research funding and nearly $18 million awarded directly for stomach cancer research grants.

www.DebbiesDream.org
Debbie's Dream Foundation
CURING STOMACH CANCER

What are you searching for?

Raising Awareness. Funding Research. Supporting Patients. Achieving the DREAM!
Debbie's Dream Foundation: Curing Stomach Cancer (DDF) is dedicated

News
September 12, 2018 – H. pylori test hints at risk factor for stomach cancer
Helicobacter pylori, a specific strain of bacteria found more often in East Asian patients, may be a risk factor for...

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VIEW EVENTS
# Debbie’s Dream Foundation: Curing Stomach Cancer

## Upcoming Events

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Debbie’s Dream Foundation: Curing Stomach Cancer
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General Inquiries: Admin@DebbiesDream.org
Patient Resources: Patient.Resource@DebbiesDream.org
Events: Events@DebbiesDream.org
Communications: Communications@DebbiesDream.org
Adam Bass, MD
Dana-Farber Cancer Institute

- Associate Professor of medicine at Harvard Medical School
- Physician/scientist at the Dana-Farber Cancer Institute and Brigham and Women’s Hospital
- Associate member of the Broad Institute
- Undergraduate degree from Amherst College and his MD degree at Duke University School of Medicine
- He pursued clinical training in internal medicine at the Massachusetts General Hospital and medical oncology at the Dana-Farber/Partners Cancer Center. At the completion of his clinical training, he was a post-doctoral fellow with Dr. Matthew Meyerson at both the Dana-Farber Cancer Institute and Broad Institute.
- Studies the genomics and biology of stomach and esophageal cancer.
- Co-led efforts to map the genomes of these diseases through The Cancer Genome Atlas.
- Currently working to define the action of specific cancer causing genes in these cancers and to develop new therapeutic approaches.
- New studies of the genome are aiming to understand correlates of genomics of these cancers with clinical phenotypes and to understand how these cancers evolve during therapy.
The Esophageal and Stomach Cancer Project: Patient-Engaged Research

Debbie’s Dream Foundation Webinar
January 23, 2019

Adam Bass, MD
Associate Professor of Medicine
Harvard Medical School
Dana-Farber Cancer Institute
Associate Member; Broad Institute
What if we could generate a public database of clinical, genomic, molecular, and patient reported data in cancer to enable researchers to find patterns in the data – and help accelerate discoveries and the development of new treatment strategies?
Enable cancer patients anywhere to share their information and samples with researchers everywhere
Where we are going....
What’s the point?
How is this going to help?
Let’s Take a Step Back

- Cancer is ‘A disease of the Genome’
- Genome = the DNA in each Cell
- The DNA is the ‘cookbook’ for making proteins that do the work in each cell
- Genes for proteins that make cells grow can be ‘activated’ in cancer cells
- Genes for proteins that stop cell growth can be ‘turned off’ in cancer cells
Genomic Profiling and Cancer Therapy #1

- Tumors become dependent upon pro-growth genes turned on by my genetic mutation.

- Drugs that effectively block these activated genes can be highly effective.
  - But different patients have different activated ‘genes’ so different patients with the ‘same’ cancer may need different drugs!

- **Big idea**: Genomic profiling of each cancer may help us select optimal targeted drugs for each tumor.
  - This is why we do HER2 testing in stomach/esophageal cancer and many patients get additional testing.
Genomic Profiling and Cancer Therapy #2

- The different genetic and molecular features of each cancer impact cancer behavior
  - How likely are specific cancers to recur after surgery?
  - How well will specific cancers respond to different therapies and how long do responses last?
- However, we do not know enough about how stomach cancers’ features impact their behavior
- To address this problem, we need information on the genetics/molecular aspects of a tumor and on the clinical outcomes of the patient. And we need this information from a lot of patients
Why is all of this helpful?

• If we can find the features that predict cancer behavior, we can ultimately use these features to select optimal therapy

• If we can find the tumor features that predict resistance to therapy, we can develop new and better therapies

• All of this will allow us to better understand how stomach cancer ‘works’
  – And understanding how cancer works can lead to many advances, often unexpected
Challenges of Studying Patient Tumor Samples

- Most patients’ samples and data have not been readily available for study
- 85% of U.S. cancer patients are treated in community settings

Technology, social media, and cultural changes now provide a new opportunity to engage cancer patients and directly partner with them in this research.
The Scientific Need in Cancer Research

- **Ultimate goal:** To understand what drives cancer so that we eventually can interpret every patient’s cancer genome, identify the optimal treatments, and anticipate and preempt resistance before it arises.

- There’s been a lot of progress, but we still have much work to do.

- What will it take to get there? Detailed molecular and genomic characterization of **thousands** of tumor and germline samples along with clinical, pathologic, and radiologic data.
Enable cancer patients anywhere to share their information and samples with researchers everywhere

https://joincountmein.org/
A non-profit organization aimed at making it possible for cancer patients anywhere in the United States and Canada to be partners in cancer research.

Over the next few years, Count Me In aims to launch projects in every major cancer type as well as pediatric and rare cancers.
Help transform our understanding of metastatic breast cancer.

If you have metastatic breast cancer, join a nationwide movement of patients, doctors, and scientists by sharing your tumor samples, your medical information, and your voice. Together, we can speed the development of future therapies.
What is this?

• A research study approved by the Dana Farber Cancer Institute IRB (Ethics Board)
• Patients anywhere in country can sign up online and share basic clinical information and give consent for:
  – Count Me In team to obtain clinical records to collect data
  – Count Me In team to obtain extra tumor samples from hospital/clinics and get DNA and perform genomic and molecular analysis on the tumor
  – Us to share the data (not identified to patients) across research community
Become part of the research movement. Have a direct impact on the future.

By saying "Count Me In", you will partner with leading research institutes, hospitals, and patient advocacy groups by sharing part of your stored tumor tissue and copies of your medical records.

Here's how you can participate

1. **Tell us about yourself**
   
   Click "Count Me In" and complete a simple online form to tell us about yourself and your cancer. Our goal is to perform many different studies within the metastatic breast cancer community, so allowing us to know a little bit about your experience will help us design future studies.

2. **Give us permission to collect your samples and data**
   
   When we start a study that matches what you have told us about yourself, we will ask you to fill out an online consent form that requests your permission to obtain copies of your medical records and some of your stored tumor tissue. We will do the rest - we'll contact.

3. **Learn with us along the way**
   
   We are excited to learn with you! Throughout the project, we will provide you with regular updates about the status of the project and share any discoveries that you have enabled us to make. We also may ask you additional questions about your experience to help with...
Over **5000 women and men** with metastatic breast cancer from all 50 states have joined the MBCproject since our launch in October 2015
MBCproject: Patients Registered, Consented, and Samples Received

- registered
- consented
- saliva received
- blood received

- 850 medical records received
- 420 tumors from >300 patients
- 300 tumors with DNA sequencing
- >1000 blood sample

- >5000
- >2800
- >1900
- >1000
Over 1700 Institutions Represented

- 1236 institutions with 1 patient (420 patients total)
- 19 institutions with 10+ patients
  - MD Anderson (70 patients)
  - DFCI (65 patients)
  - MSKCC (51 patients)
  - U Penn (24 patients)
  - Seattle Cancer Care (22 patients)
  - UCSF (20 patients)

MBCproject Top 20 Institutions

<table>
<thead>
<tr>
<th>Institution Name</th>
<th>Number of Patients</th>
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<tbody>
<tr>
<td>UT M. D. ANDERSON CANCER CENTER</td>
<td>70</td>
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<tr>
<td>DANA-FARBER CANCER INSTITUTE</td>
<td>65</td>
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<tr>
<td>MEMORIAL SLOAN KETTERING CANCER CENTER</td>
<td>51</td>
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<td>UNIVERSITY OF PENNSYLVANIA - ABRAMS CANCER CENTER</td>
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<tr>
<td>SEATTLE CANCER CARE ALLIANCE - SEATTLE</td>
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<td>UCSF MEDICAL CENTER</td>
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<tr>
<td>MÖRFFTT CANCER CENTER</td>
<td>19</td>
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<tr>
<td>MAYO CLINIC HOSPITAL ROCHESTER</td>
<td>18</td>
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<tr>
<td>MASSACHUSETTS GENERAL HOSPITAL</td>
<td>15</td>
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<tr>
<td>OAKS UNIVERSITY HOSPITAL</td>
<td>15</td>
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<tr>
<td>CITY OF HOPE NATIONAL MEDICAL CENTER</td>
<td>14</td>
</tr>
<tr>
<td>UNIVERSITY OF UTAH - HUNTSMAN CANCER INSTITUTE</td>
<td>12</td>
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<tr>
<td>NEW YORK HOSPITAL/WEILL-CORNELL</td>
<td>12</td>
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<tr>
<td>MAGEE WOMENS HOSPITAL OF UPMC HEALTH SYSTEM</td>
<td>12</td>
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<tr>
<td>YALE-NEW HAVEN - SMILLOW CANCER CENTER</td>
<td>11</td>
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<tr>
<td>FOX CHASE CANCER CENTER (TEMPLE HEALTH)</td>
<td>11</td>
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<tr>
<td>UCLA MEDICAL CENTER</td>
<td>10</td>
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<tr>
<td>NORTHWESTERN MEMORIAL HOSPITAL</td>
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</tr>
<tr>
<td>CLEVELAND CLINIC - MAIN CAMPUS</td>
<td>10</td>
</tr>
<tr>
<td>WILLOTTTE VALLEY MEDICAL CENTER - HR-HOOver MD CANCER CENTER</td>
<td>9</td>
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An Open Clinico-genomic Database

All somatic and germline genomic data and linked clinical data deposited every 6 months

PATIENT AND RESEARCHER SPECIFIC PORTALS
Clinically annotated WES of 237 tumors from 180 patients (132 mets, 105 primaries; 42 matched pairs/series) available cbioportal.org

An Open Clinico-genomic Database

5500 downloads from cbioportal.org
Viewed over 80,000x
Why is this different?

- Patient centered – including patients treated in the community
- Enables more diversity in research
- Potential to enroll large numbers of patients – allows study of questions that require large numbers plus studies of rare subgroups
- Convergence of clinical, genomic, patient reported – all linked and able to be linked to other data sets
- Data is shared publicly as it is generated
- **Patient-researcher partnership: patients can be re-contacted based on our learning**
“I want to live and watch my children grow up, but if I can’t, then I want to leave a legacy and a cure.”
—Houston, TX

“As someone who does not live near a research center and therefore cannot easily participate in trials, I finally feel like I can contribute.”
—Lake Tahoe, CA

“Amazing how happy that little box makes you feel! I felt like a 2 year old. Let me help! I feel a sense of pride and belonging because of this.”
—Minneapolis, MN

“Giving us HOPE for the future and if not for some of us, for our families.”
—Scottsdale, AZ
Can we do this in other cancers?
371 women and men with angiosarcoma have joined the ASCproject since March 2017. Over 125 people have filled out information on behalf of a loved one who died from angiosarcoma.
48 samples from 36 patients publicly shared

Over 4,000 views in the past 6 months; ~30 pageviews per weekday

Initial studies using this data are in progress
The Metastatic Prostate Cancer Project
MPCproject.org

You can have a direct impact on the future of men with prostate cancer.

The Metastatic Prostate Cancer Project is a nationwide genomic research study for men with advanced or metastatic prostate cancer. We seek to generate the most comprehensive database that will be shared with the entire research community to accelerate discoveries.
Have a direct impact on the future of Gastro-Esophageal Cancer

If you have been diagnosed with esophageal or gastric/stomach cancer, join a nationwide initiative of patients, doctors, and scientists by sharing your tumor samples, your medical information, and your voice. Together we can develop a comprehensive resource to accelerate discoveries that may inform future therapies.
You can have a direct impact on the future of Esophageal and Stomach Cancer

If you have been diagnosed with esophageal or gastric/stomach cancer, join a nationwide initiative of patients, doctors, and scientists by sharing your tumor samples, your medical information, and your voice. Together we can develop a comprehensive resource to accelerate discoveries that may inform future therapies.
How Does This Work?

• Any patient with a diagnosis of (or history of) stomach or esophageal cancer can sign up
  – Enroll at escproject.org
• Take a ~5-10 minute online survey detailing treatment history
• Choose if they want to consent to additional studies
  – Allowing team to obtain and medical records and to obtain and profile tumor tissue samples (from old surgery or biopsy)
  – Provide samples of blood and saliva
Saliva?

• We send a ‘kit’ with container for saliva/spit.
• You fill it and mail it back to us in the package we provide
• Saliva is used as source to get normal DNA
  – Normal DNA is used as a comparison to cancer DNA
  – Normal DNA is also way to identify the genetic variations that we all inherit, some of which may associate with cancer behavior
Blood??

• Burgeoning field of cancer DNA that is ‘shed’ into blood from tumors
  – New exciting method to study cancer DNA
• We send you blood collection kits with special blood tubes for getting circulating tumor DNA
• You bring the tube to clinic during regular blood work or can get blood drawn at special participating labs (our team can help)
• Mail the tube back in the provided special envelop/kit
How do I provide records and tumor samples??

• You don’t have to do anything
• If you consent, our team handles everything
  – Requesting records from the clinic/hospital
  – Extracting information from records
  – Identify if there is a sample from which we can collect material for research
    • Note, we will not deplete samples in case material is needed for future clinical testing
Where are we now?

• 109 stomach/esophageal cancer patients have signed up.
• 81 saliva kits sent; 47 received back
• 71 blood kits sent; 34 received back
• 27 med records requested; 20 received
Where are we going?

- Goal to expand to many more patients
- Goal to make this project study patients during the course of their cancer care
  - Additional surveys to track how treatments change and how tumors respond
  - Serial blood collections so we can study how the tumor DNA evolves during therapy, especially to learn how tumors become resistant to therapy
  - Additional ways to study tumors, such as looking at features of the immune system
Objective: To generate a publicly available database of clinical, genomic, molecular, and patient reported data in cancer to accelerate discoveries and the development of new treatment strategies.
A Few Potential Questions

• Will my identity be revealed?
  – No, patients are listed by code number

• Will I get my data back?
  – As this is research, we are not legally allowed to report back data

• Can I withdraw consent?
  – Yes, at any time
More Potential Questions

• Will my data be sold?
  – No, data will be placed on public repositories that are used by researchers (across world, including working for government, academics and industry)

• Who is paying for this?
  – This is funded by philanthropic donations
Ways to Help

• Sign Up
  – And post on social media

• Become a patient ambassador
  – Help reach/recruit additional patients, including on online patient communities

• Participate in our working group to help develop new questions, shape how we engage with patients
Acknowledgements

- Eli Van Allen
- Adam Bass
- Jim Palma
- Tania Simoncelli
- Jesse Boehm
- Gad Getz
- Andrew Zimmer
- Blake Skinner
- Cameron Ardell
- Charlotte Dye
- Diane Kaplan
- Esme Baker
- Kiara Westbrooks
- Marco Ocana
- Mikhail Aleksandrov
- Pavel Sidorenko
- Rich Nordin
- Sampath Settipalli
- Sergei Retsia
- Simone Maiwald
- David Oluwadara
- Gene Hui
- Jeff Korte
- Jen Lapan
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- Rob Meffan
- Scott Sutherland
- David Siedzik
- Anthony Philippakis
- DSP / Pepper / DSM
- Jared Cosulich
- Playground, Inc
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- Elana Hale
- Samantha Singer
- Jesse Souweine
- Justine Levin-Allerhand
- Todd Golub
- Eric Lander
- Advocacy Partners
- All Participating Patients
Questions and Answers

www.DebbiesDream.org
Speaker Information and Link to Slides

Andrea Eidelman, Esq. – Executive Director
Debbie’s Dream Foundation:
Curing Stomach Cancer
www.debbiesdream.org

Adam Bass, MD
Dana-Farber Cancer Institute
Boston, MA

URL Link to Today’s Slide Presentation:

https://debbiesdream.org/lecture-library/
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The Esophageal and Stomach Cancer Project: Patient-Engaged Research

We’d love to hear from you with questions for our upcoming webinar
Patient.Resource@DebbiesDream.org

For more information regarding this webinar and other activities, contact:
Debbie’s Dream Foundation: Curing Stomach Cancer

www.DebbiesDream.org