5th Annual Patient and Family Centered Care For Pancreatic Disease

Saturday, October 9, 2021
11:30 am – 2:30 pm • Virtual Meeting (due to Covid-19)

11:30 am Welcome
Matthew DiMagno, MD - Course Director

11:40 MM Comprehensive Pancreas Program Updates
Richard Kwon, MD

11:50 NPF Michigan Chapter Updates
Robin Winke, LMSW

12:00 pm Clinical Problem - Maldigestion
Erik-Jan Wamsteker, MD

12:05 Patient Testimony

12:15 Keynote: Dietary Management
Amanda Lynett, MS, RD

12:30 pm Panel Discussion

12:55 Break

1:10 Genetic Causes of Pancreatic Diseases - Case-Based Discussions
Elena Stoffel, MD, MPH
Tannaz Guivatchian, MD
Andrea Murad, CGC

1:35 Keynote: GI Genetics Clinic
Elena Stoffel, MD

2:00 Panel Discussion

2:25 Parting Comments

2:30 Adjourn

Pre-registration required by October 1st, 2020

To Register
https://michmed.org/L10vY

To Donate
https://michmed.org/x012W

Event Partners: AbbVie, Chiesi, Nestle and Vivus
Syllabus Table of Contents

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About this Event

On October 9, 2021, Michigan Medicine and the National Pancreas Foundation Michigan Chapter will host the 5th Annual Patient and Family Centered Care for Pancreatic Diseases educational event. Due to the ongoing Covid-19 pandemic, we will host a virtual rather than an in-person program.

Our patient and family education events serve as an opportunity to bring healthcare professionals and experts in pancreas disease in contact with patients and caregivers in an informal setting to enable the sharing of information on new developments in the treatment and care of pancreas disease.

The main goals are to increase understanding of the relationship between abnormal digestion and pancreatic diseases; ways to improve or maintain nutrition; genetic causes of pancreatitis, pancreatic insufficiency, and pancreatic cancer; and what happens during genetic counseling sessions. We will also discuss updates and resources available at the Michigan Medicine Comprehensive Pancreas Program and the National Pancreas Foundation (NPF) Michigan Chapter.

Amanda Lynett, MS, RDN, Division of Gastroenterology, Michigan Medicine, will deliver the first keynote address, entitled, Dietary Management (in those with pancreatic disorders).

Elena Stoffel, MD, MPH, Clinical Associate Professor of Medicine, Division of Gastroenterology, Michigan Medicine, will deliver the second keynote address, entitled, GI Medical Genetics Evaluation for Pancreatic Diseases.

The event is free and open to all physicians, patients, and caregivers. Please register by October 2, 2021.

Consider Donating to the 6th Annual Educational Event (October 2022)

https://leadersandbest.umich.edu/find/#!/give/basket/fund/331933

Event Partners

Michigan Medicine Comprehensive Pancreas Program

National Pancreas Foundation - Michigan Chapter

AbbVie

Vivus

Chiesi

Nestle
Speaker Biographies

*Matthew J. DiMagno, MD* is Associate Professor of Internal Medicine, Division of Gastroenterology, Michigan Medicine, University of Michigan, where he has been faculty since 2001. He is a Pancreatologist with expertise in clinical care and research in pancreatitis, exocrine pancreatic insufficiency, and other pancreatic disorders. He is author/co author of over 71 peer reviewed publications and book chapters. He has received NIH grant funding for study of acute and chronic pancreatitis. He formerly served as Chair of the American Gastroenterological Association Institute Council Pancreatic Disorders Section Committee. Currently he serves Director of the Michigan Medicine Comprehensive Pancreas Program in Gastroenterology, Gastroenterology Director of the Adult CF Center, and Course Director of the 5th Annual Patient and Family Centered Care for Pancreatic Diseases.

*Medical Director, The National Pancreas Foundation Michigan Chapter*

*Richard Kwon, MD* is Associate Professor of Internal Medicine, Division of Gastroenterology, Michigan Medicine, University of Michigan, where he has been faculty since 2005. He is a pancreatologist and interventional endoscopist with clinical expertise in pancreatic cystic neoplasms, pancreatic cancer, and acute and chronic pancreatitis. He has authored/coauthored over 20 papers on the role of endoscopy and technology in the management of cystic neoplasms, pancreatic cancer, and complications of both acute and chronic pancreatitis. He has received grant funding for studies related to pancreatic cystic neoplasms. He is an active member of multiple major pancreatic and GI associations.

*Board Member, The National Pancreas Foundation Michigan Chapter*

Robin Winke, LMSW attended Michigan State University where she was awarded her Master’s Degree in Social Work and certificate in Family Counseling. She completed her undergrad at Oakland University and has a Business degree. She is a therapist at Wink Counseling, P.C., located in Troy. Her focus is on older adults, chronic illnesses, and family dynamics. Her volunteer experience includes crisis counseling, transitional housing advocate and other local service programs for older adults.

*Chair, The National Pancreas Foundation Michigan Chapter. She is personally responsible for launching the chapter and establishing a monthly support group meeting. She is married to Derrick Winke, a survivor of pancreatitis.*

*Erik Jan Wamsteker, MD* is Associate Professor of Internal Medicine, Division of Gastroenterology, Michigan Medicine, University of Michigan, where he has been faculty since 2002. His clinical focus has been in the diagnosis and treatment of patients with benign and malignant pancreatic diseases and performs therapeutic endoscopic procedures on patients with pancreatic disorders and their complications. He serves on national committees where he specifically focuses on the dissemination of new knowledge and education through the creation and updating of guidelines in pancreatic diseases through the American Gastroenterological Association (AGA) and the American College of Gastroenterology (ACG) and as a counselor for the pancreatic disorders section of the AGA for Digestive Disease Week.

*Board Member, The National Pancreas Foundation Michigan Chapter*
*Georgiann Z.* We are fortunate to have the opportunity to hear about the remarkable experiences of Georgiann Z, a patient who receives care at Michigan Medicine. Until she began her journey with pancreatic disease, she was employed by United Auto Workers. Currently she serves as a patient advisor on numerous committees and boards at Michigan Medicine, all aimed at improving the lives and experiences of patients. These include the Patient and Family Centered Care Committee; Emergency Department and Hospital 6B Unit Committees; Doctoring Program (mentoring 1st year Medical students), Cardiovascular Center Executive Board Committee, Michigan Institute for Clinical and Health Research review committee, Medicare Beneficiary Chair, and Ambassador to the Patient Centered Outcomes Research Institute (PCORI)

*Board Member, The National Pancreas Foundation Michigan Chapter*

**Amanda Lynett, MS, RDN** is Registered Dietician, Division of Gastroenterology, Michigan Medicine, University of Michigan. Her clinical focus includes the low FODMAP diet for managing Irritable Bowel Syndrome, Exocrine Pancreatic Insufficiency, and Gastroparesis as well as providing other individualized nutrition counseling for a variety of gastrointestinal disorders. She has participated as invited speaker at national meetings on the topic of managing nutritional complications of patients with pancreatic insufficiency. This includes the 4th Annual GI Nutrition Training program for Registered Dietitians 2019, the 3rd Annual Patient and Family Centered Care for Pancreatic Disease, and the May 2021 Digestive Disease Week meeting.

**Tannaz Guivatchian, MD** is Assistant Professor of Internal Medicine, Division of Gastroenterology, Michigan Medicine, University of Michigan where she has been faculty since 2015. Dr. Guivatchian is a general gastroenterologist and specializes in hereditary gastrointestinal cancer diagnosis and management. She participates in the multidisciplinary Gastrointestinal Cancer Genetics Clinic Program at Michigan Medicine and is also involved in clinical research in the field. Her clinical interests additionally include medical student education.

**Andrea M Murad, MS, CGC** is Lead Genetic Counselor, Cancer Genetics Clinic, Department of Internal Medicine, Michigan Medicine, University of Michigan. Her research interests include health disparities in genetic counseling and the process of returning secondary or incidental findings on genetic tests and their integration into patient care. She is currently the Vice President of the Michigan Association of Genetic Counselors, the Vice Chair of the Practice Guidelines Committee of the National Society of Genetic Counselors (NSGC) and was selected as an author for the Hypertrophic Cardiomyopathy Guidelines Systematic Review. She also supervises genetics residents, genetic counseling students, medical students, and hematology/oncology fellows in the Cancer Genetics Clinic.

**Elena M Stoffel, MD, MPH** is Associate Professor of Internal Medicine, Division of Gastroenterology, Michigan Medicine, University of Michigan. Her clinical and research interests encompass early detection and prevention of gastrointestinal cancers, as well as diagnosis and management of individuals with genetic predisposition. She is an investigator funded by the National Institute of Health. She has served in numerous leadership rounds within Michigan Medicine and Nationally. Dr. Stoffel serves on the ASCO Committee for Cancer Genetics and is a past President of the Collaborative Group of the Americas on Inherited Colorectal Cancer (CGA ICC).
Abbreviations

ACT, acceptance and commitment therapy
AGAF, American Gastroenterological Association Fellow
ATA, accredited tax advisor
ATM, ataxia telangiectasia
ATP, accredited tax preparer
BRCA, breast cancer gene
CAP, certified administrative profession
CaSR, calcium sensing receptor
CBD, cannabidiol
CBT, cognitive behavioral therapy
CDE, certified diabetes educator
CDKN2A, cyclin dependent kinase inhibitor 2A
CF, cystic fibrosis
CFTR, cystic fibrosis transmembrane conductance regulator
CGC, clinical genetics counselor
CGM, continuous glucose monitor
CME, continuing medical education
COE, center of excellence
CP, chronic pancreatitis
CT, computed tomography (CAT scan)
CTRC, chymotrypsin C
DEXA, dual energy X ray absorptiometry (bone density test)
DM, diabetes mellitus
DNA, deoxyribonucleic acid
EPI, exocrine pancreatic insufficiency
ERCP, endoscopic retrograde cholangiopancreatography
EUS, endoscopic ultrasonography
FACS, Fellow, American College of Surgeons
FASGE, Fellow American Society Gastrointestinal Endoscopy
GE, gastroenterologist
GI, gastrointestinal
GP, general practitioner
HFE gene, high FE2+ gene (hemochromatosis gene)
IBD, inflammatory bowel disease
LMSW, Licensed Master Social Worker
MBA, Master of Business Administration
MCT, medium chain triglycerides
MD, Doctor of Medicine
MLH, mutL homolog 1
MM, Michigan Medicine
MPH, Master of Public Health
MRI, magnetic resonance imaging
MSH, melanocyte stimulating hormone
MSc, Master of Science
NIH, National Institutes for Health
NPF, National Pancreas Foundation
PA, physician assistant
PALB2, partner and localizer of BRCA2
PARP, poly (ADP ribose) polymerase
PD, pancreatic duct
PhD, Doctor of Philosophy
PERT, pancreatic enzyme replacement therapy
PMS, photopheriod sensetive genic male sterility
PRSS1, serine protease 1 (cationic trypsinogen)
PsyD, Doctor of Psychology
QOL, quality of life
RD, registered dietician
REE, resting energy expenditure
**SIBO**, small intestinal bacterial overgrowth

**SPINK1**, small intestinal bacterial overgrowth

**STK11**, serine/threonine kinase 11

**THC**, tetrahydrocannabinol

**VUS**, variant of unknown significance
Weblinks

Michigan Medicine, Comprehensive Pancreas Program – Gastroenterology

- [https://medicine.umich.edu/dept/intmed/divisions/gastroenterology_hepatology/programs/comprehensive_pancreas_program](https://medicine.umich.edu/dept/intmed/divisions/gastroenterology_hepatology/programs/comprehensive_pancreas_program)
  
  To donate
- [https://michmed.org/xo12W](https://michmed.org/xo12W)

Michigan Medicine, Pancreatic Cancer Clinic – Cancer Center

- [https://www.rogelcancercenter.org/pancreatic_cancer/clinic](https://www.rogelcancercenter.org/pancreatic_cancer/clinic)
- [https://pancreas.med.umich.edu/](https://pancreas.med.umich.edu/)

National Pancreas Foundation, Michigan Chapter

*Home page – board, educational events, support group meeting*

- [https://pancreasfoundation.org/state_chapters/michigan/](https://pancreasfoundation.org/state_chapters/michigan/)

  To donate (fundraising walk 11/13/21, 11:30 AM, Paint Creek Cider Mill, MI)
- [https://give.pancreasfoundation.org/ge/pancwalk](https://give.pancreasfoundation.org/ge/pancwalk)

National Pancreas Foundation (NPF)

*Home page*

- [https://pancreasfoundation.org/](https://pancreasfoundation.org/)

*NPF Centers of Excellence*

- [https://pancreasfoundation.org/npf_centers_info/](https://pancreasfoundation.org/npf_centers_info/)

*State chapters*

- [https://pancreasfoundation.org/state_chapters/](https://pancreasfoundation.org/state_chapters/)

*About the pancreas*

- [https://pancreasfoundation.org/patient_information/about_the_pancreas/](https://pancreasfoundation.org/patient_information/about_the_pancreas/)

*Animated pancreas patient*

- [https://pancreasfoundation.org/patient_information/animated_pancreas_patient/](https://pancreasfoundation.org/patient_information/animated_pancreas_patient/)
Attendee Action Items: Pre- and Post-Event Surveys

Complete 5 days before program
- Complete all true/false question to be entered into a random drawing for prizes.

Please circle true or false for each question

1. **Kwon**  NPF center designation requires multidisciplinary expertise in pancreatic diseases __True  False
2. **Winke**  The NPF Michigan chapter has support group meetings once per month __True  False
3. **Wamsteker**  Severe pancreatic insufficiency (maldigestion) is treated with pancreatic enzymes __True  False
4. **Patient**  Patient family involvement does not make a difference in clinical outcomes __True  False
5. **Lynett**  Pancreatic maldigestion can cause weight loss, muscle wasting and osteoporosis __True  False
6. **Lynett**  Recommended dietary fat is 30% of total for patients with pancreatic maldigestion __True  False
7. **Guivatchian**  Genetic testing for pancreatitis is only for patients with a family history __True  False
8. **Murad**  Genetic testing for pancreatic cancer is most often performed by blood testing __True  False
9. **Stoffel**  Genetic counseling includes counseling of family members __True  False

Please submit questions you have for presenters to answer during the panel discussions

Questions about pancreatic insufficiency: ________________________________________________________________

Questions about nutrition: ______________________________________________________________

Questions about Genetic testing: ______________________________________________________________

Other questions: ______________________________________________________________
Complete within 5 days after program

- Complete all true/false question to be entered into a random drawing for prizes.

Please circle true or false for each question

1. Kwon Michigan Medicine is the only National Pancreas Foundation Center in Michigan True False
2. Winke The NPF Michigan chapter has support group meetings once per month True False
3. Wamsteker Diabetes mellitus is rare in patients with chronic pancreatitis or cancer True False
4. Wyckoff Patients with diabetes and chronic pancreatitis always require insulin True False
5. DiMagno Abdominal pain is present in all patients with chronic pancreatitis True False
6. Wiley Cannabis relieves pain in the majority of patients with chronic pancreatitis True False
7. Riehl Behavioral therapy for pain is under utilized in patient with chronic pancreatitis True False

Please evaluate the overall quality of program below

<table>
<thead>
<tr>
<th></th>
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<th>Disagree</th>
<th>Undecided</th>
<th>Agree</th>
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<td>This event was valuable to me</td>
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<td>I will attend next year’s event?</td>
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What topics are interesting to you? Please rank from 1 (preferred) to 9 (least preferred)

a. Abdominal pain: (1 9)
b. Pancreatic enzymes: (1 9)
c. Nutrition: (1 9)
d. Diabetes: (1 9)
e. Pancreatic cancer: (1 9)
f. Pancreatic cysts: (1 9)
g. Pancreatic surgery: (1 9)
h. Endoscopic procedures: (1 9)
i. Other: (1 9)

If “other” please list here: ___________________________
Past Annual Educational Events (2017-2021) and Materials

2021  *Maldigestion and Genetics*  
Virtual (due to Covid-19)  
University of Michigan Medical Campus  
125 registrations; 15 states, 6 countries  
[Link to syllabus & Video]

2020  *Diabetes and Pancreatic Pain*  
Virtual (due to Covid-19)  
University of Michigan Medical Campus  
256 registrations; 40 states, 5 countries  
[Link to syllabus & Video]

2019  *Maldigestion and Pancreatic Cancer*  
Live, Inn at St Johns, Plymouth, Michigan  
75 attendees; 95% planned to return  
[Link to syllabus]

2018  *Complex Care and Pancreatic Pain*  
Live, Inn at St Johns, Plymouth, Michigan  
80 attendees; 95% planned to return

2017  *Patient/Family Centered Care and NPF Centers*  
Live, Inn at St Johns, Plymouth, Michigan  
35 attendees; 87% planned to return
Mark Your Calendar October 2022 (1st or 22nd)

6TH ANNUAL
Patient and Family Centered Care for PANCREATIC DISEASES
Saturday, OCTOBER 2022 (1st or 22nd)
11:30 am – 2:30 pm
The Inn at St Johns, Plymouth, Michigan

REGISTER
https://give.pancreasfoundation.org/ge/pancwalk
<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Presenter(s)</th>
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<tbody>
<tr>
<td>11:30 am</td>
<td>Welcome</td>
<td>Matthew DiMagno, MD - Course Director</td>
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<td>MM Comprehensive Pancreas Program Updates</td>
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<td>1:10</td>
<td>Part II. Genetics</td>
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Welcome

5TH ANNUAL Patient and Family Centered Care for PANCREATIC DISEASES
OCTOBER 9, 2021

Matthew J. DiMagno, MD
Associate Professor of Internal Medicine
Medical Director, NPF Michigan Chapter
BRIEF ANNOUNCEMENTS

• Welcome!

• About the Annual Educational Event
  • 5th year
  • Developed program content in response to attendees’ interests
  • Selected exceptional panel of speakers
  • Increased attendance in 2020: 256 registrations, 40 states, 5 countries
  • Thankful for generous support to sustain annual events
BRIEF ANNOUNCEMENTS

Virtual webinar format

- Submit questions through registration site prior to meeting
- Panelists answer selected questions
- Unable to accept live questions, a strength of past programs

• Please respond to pre- and post-event communications
  - Complete 9 true/false questions (pre- and post-event)
    -> provides a measure of learning and effectiveness of speakers
    -> eligible for a drawing for prizes, for completing pre- and post-event
  - Suggest topics for next year's program to meet your needs

• Receive email with link to course syllabus and video
  - 5th Annual Event (Oct 9, 2021): available in 2 weeks
  - 4th Annual Event (Oct 17, 2020): SEE here

HOPE
BRIEF ANNOUNCEMENTS

• See 4th Annual Event (Oct 17, 2020) syllabus and video here

Digestive and Liver Health

Pancreatic Disorders

The pancreas is a gland that sits behind the stomach and plays a key role in the digestive system. It supplies the intestines with digestive enzymes that split the fats, proteins and carbohydrates in your diet into digestible molecules, and it produces insulin and other hormones that control your body’s ability to use sugar (glucose).

Pancreatic disorders include:
- Pancreatitis
- Exocrine pancreatic insufficiency (EPI)
- Cystic Fibrosis (CF), associated GI disorders
- Pancreatic Cancer

Mark Your Calendar
October 2022
(1st or 22nd)

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Patient and Family Centered Care for
PANCREATIC DISEASES

Saturday, OCTOBER 2022 (1st or 22nd)
11:30 am – 2:30 pm
The Inn at St Johns, Plymouth, Michigan
TODAY’S PROGRAM GOALS

Updates: Michigan Medicine Comprehensive Pancreas Program
         National Pancreas Foundation Michigan Chapter

1. Increase understanding of the relationship between abnormal digestion and pancreatic diseases; ways to improve or maintain nutrition

   15 min break

2. Highlight genetic causes of pancreatitis, pancreatic insufficiency and pancreatic cancer; and what happens during genetic counseling sessions.

THANK YOU

Partners  AbbVie    Chiesi    Nestle    Vivus

Planning  Michigan Medicine Comprehensive Pancreas Program
          The National Pancreas Foundation
          Michigan Chapter
          Board Members
          *Vicky Vincent, Board Secretary
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Patient and Family Centered Care for
PANCREATIC DISEASES
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Panel Discussion

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Genetic Causes of Pancreatic Diseases – Case-Based Discussions
Andrea Murad, MS, CGC
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Keynote Presentation: GI Genetics Evaluation for Pancreatic Diseases
Elena Stoffel, MD, MPH

Panel Discussion

MM Comprehensive Pancreas Program Updates

5TH ANNUAL
Patient and Family Centered Care for
PANCREATIC DISEASES
OCTOBER 9, 2021

Richard Kwon, MD
Associate Professor of Internal Medicine
Board Member, NPF Michigan Chapter
Industry Relationship Disclosures
Industry Supported Research and Outside Disclosures

- Abbvie (research)
1. PATIENT-CENTERED CLINICAL CARE

THE COMPREHENSIVE PANCREAS PROGRAM

2. MULTIDISCIPLINARY COLLABORATION

3. INNOVATIVE RESEARCH

4. EDUCATION

CHRONIC PANCREATITIS
AUTOIMMUNE PANCREATITIS
PANCREATIC INSUFFICIENCY

ACUTE PANCREATITIS
NECROSIS
PSEUDOCYSTS

CYSTIC FIBROSIS

NEOPLASMS
CYSTIC
PANCREATIC AMPULLARY

CLINICAL CARE

HEREDITARY PANCREATITIS
HEREDITARY/FAMILIAL PANCREATIC CANCER
THE COMPREHENSIVE PANCREAS PROGRAM

CLINICAL CARE

TAUBMAN CENTER

CANCER CENTER

WEST ANN ARBOR

GENETICS CLINIC

1. PATIENT CENTERED CLINICAL CARE

2. MULTIDISCIPLINARY COLLABORATION

3. INNOVATIVE RESEARCH

4. EDUCATION
THE COMPREHENSIVE PANCREAS PROGRAM

MULTIDISCIPLINARY TUMOR BOARD

1. PATIENT CENTERED CLINICAL CARE
2. MULTIDISCIPLINARY COLLABORATION
3. INNOVATIVE RESEARCH
4. EDUCATION
THE COMPREHENSIVE PANCREAS PROGRAM

FIRST IN MICHIGAN

1. PATIENT CENTERED CLINICAL CARE
2. MULTIDISCIPLINARY COLLABORATION
3. INNOVATIVE RESEARCH
4. EDUCATION
THE COMPREHENSIVE PANCREAS PROGRAM

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Tannaz Guivatchian, MD

1:35  Keynote Presentation: GI Genetics Evaluation for Pancreatic Diseases  
Elena Stoffel, MD, MPH  
Panel Discussion
The National Pancreas Foundation provides hope for those suffering from pancreatitis and pancreatic cancer through funding cutting edge research, advocating for new and better therapies, and providing support and education for patients, caregivers, and health care professionals.

FEATURED PROGRAMS

ANIMATED PANCREAS PATIENT
NPF CENTERS
PATIENT SUPPORT COMMUNITY
PATIENT EDUCATION EVENTS
STATE CHAPTERS
OUR PHYSICIAN PROGRAMS

• RESEARCH GRANT FUNDING
  • $150,000
• MEDICAL EDUCATION
  ANNUAL PANCREAS SYMPOSIUMS AND THIRTEEN EDUCATION EVENTS IN 2021
  • NATIONAL PATIENT REGISTRY
  • ANNUAL FELLOW SYMPOSIUM
    APRIL 1-3 2022 IN DALLAS TEXAS

NPF CENTERS

The NPF has identified treatment centers for patient referrals based upon specific criteria. At an approved NPF Center, patients can expect excellent multidisciplinary care that focuses on the whole patient to include: experienced oncologists, gastroenterologists, surgeons, dietitians, pain specialists, psychosocial support and more.

Two NPF Centers in Michigan
• Michigan Medicine, University of Michigan, Ann Arbor – 1st NPF center in Michigan
• West Michigan Cancer Center, Kalamazoo
OUR STATE CHAPTERS

Dr. Matthew J. DiMagno, MD, AGAF
NPF Michigan Medical Director

Robin Winke, LMSW
Michigan Chair

NPF Michigan Board Members

Clifford S. Cho, FACS
Richard Kwon, MD
Lance Judd
Megan Morsi, PAC
Vicky L. Vincent, CAP
Erik-Jan Wamsteker, MD
Derrick Winke, ATA, ATP, MBA
Georgiann Ziegler
Support Groups

GROUPS HELP THROUGH:

I. INSTILLATION OF HOPE

II. UNIVERSITY

III. ALTRUISM

IV. INTERPERSONAL LEARNING

V. SOCIALIZING TECHNIQUES

VI. EDUCATION
Fund Raising

COLOR IT PURPLE CHALLENGE!

<table>
<thead>
<tr>
<th>ICE CREAM SOCIALS</th>
<th>PARTNERING WITH OTHER FOUNDATIONS</th>
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<tbody>
<tr>
<td>PANCREAS BOWL</td>
<td>FB CHALLENGES</td>
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</table>

ANNUAL PANC WALK

REGISTRATION

https://give.pancreasfoundation.org/ge/pancwalk
Volunteer Opportunity
Host Support Groups
Fundraising Board members
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Matthew DiMagno, MD - Course Director

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Panel Discussion

**Part II. Genetics**

Genetic Causes of Pancreatic Diseases –  
Case-Based Discussions  
Andrea Murad, MS, CGC  
Tannaz Guivarchian, MD

Keynote Presentation: GI Genetics Evaluation for Pancreatic Diseases  
Elena Stoffel, MD, MPH

Panel Discussion

**Maldigestion – Clinical Problem**

5TH ANNUAL  
Patient and Family Centered Care for  
PANCREATIC DISEASES  
OCTOBER 9, 2021

Erik-Jan Wamsteker, MD  
Associate Professor of Internal Medicine  
Board Member, NPF Michigan Chapter
Industry Relationship Disclosures

Industry Supported Research and Outside Disclosures

- None

Maldigestion - Definition

Maldigestion
- Impaired digestion, incomplete breakdown of food (nutrients) in the intestine
- Causes: pancreatic enzyme deficiency, other enzyme deficiency (i.e., Lactase)

Malabsorption
- Impaired mucosal absorption of nutrients from the intestine into the blood
- Causes: maldigestion (above) or defects in absorption or transport.

Subtle distinction between terms
- Maldigestion is one cause of malabsorption
- Terms often used interchangeably
Maldigestion - Symptoms

Diarrhea
Weight loss
Flatulence
Abdominal bloating
Cramps and abdominal pain

*Symptoms are not specific to impaired pancreatic function*

Maldigestion - Causes

**Exocrine Pancreatic Insufficiency**
- Maldigestion occurs with loss of >90% of exocrine function
- Examples: Chronic pancreatitis
  - Pancreatic surgical resection
  - Cystic fibrosis

Certain liver diseases

Small intestinal bacterial overgrowth

Enzyme deficiencies in small intestine (ie. Lactase deficiency)
Pancreatic Maldigestion - Complications

- Weight loss
- Muscle wasting
- Osteoporosis
- Visual disturbances
- Neuropathy

Discussed by Keynote speaker

Pancreatic Maldigestion - Treatment

Treatment directed at underlying disorder

- Replacement of a deficient enzyme(s)
- Pancreatic digestive enzyme replacement (PERT) during meals/snacks
  
  90,000 lipase units/meal; ½ dose for snacks

- Trouble shooting when enzymes do not work or stop working
  
  PERT dose and timing
  
  Consulting provider for evaluation for other disorders

Screening for and treating maldigestion may reduce symptoms and reduce long term complications
<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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<tr>
<td>12:00</td>
<td>Clinical Problem - Maldigestion</td>
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<td><em>Erik-Jan Wamsteker, MD</em></td>
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<td>12:05</td>
<td>Patient Testimony</td>
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<td><em>Recorded Interview</em></td>
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11:30 am  Welcome
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Georgiann Ziegler
Board Member, NPF Michigan Chapter
Georgiann Ziegler  
*Maldigestion – Patient Testimony*

**DIAGNOSIS:** Idiopathic chronic pancreatitis

**FUN FACT:** I am a brand-new grandmother

**DIAGNOSIS:** In 2004 I was diagnosed with Idiopathic Chronic Pancreatitis. Never knew where or what the pancreas did but I sure realized how painful and angry the pancreas can be. After a 65-day hospital stay in 2004, I continue to have multiple hospital stays per year. Fortunately, when not in a pancreas flare my days are good.

**SUPPORT SYSTEM:** Faith, family and friends are my greatest support team, along with my medical team. For me, I could not do this journey alone. The challenging part of all this is that most of my family and friends knew very little about the pancreas so we all learned together. I can say we are all still learning.

**LIFESTYLE CHANGES YOU’VE MADE:** I had to disability retire from a great job with the UAW in 2010. This was not only hard emotionally but financially as well. I always thought I would work to “retirement age”, have the going away lunch and walk away fulfilled. I felt cheated that my illness determined by timeline for retirement.

**WHAT THE DISEASE TAUGHT YOU ABOUT YOURSELF:**
I feel that my attitude and strength is greater than I ever could have imagine. I run with my good days and try not to worry if a flare is around the corner. If asked to go somewhere or participate in something I generally say yes with the hope that I will be well enough to go. I take my diagnosis seriously, but I do not let it steal my joy!

**WHERE ARE YOU NOW:** I continue to have pancreas flares and hospital stays. Happy to say that the admits are getting farther apart. For me, my cup will always be half full and never half empty. Because of my pancreatitis I am a patient advisor at Michigan Medicine which allows me to be a voice for not only myself but many patients and families.

**WHERE ARE YOU NOW:** I continue to have pancreas flares and hospital stays. Happy to say that the admits are getting farther apart. For me, my cup will always be half full and never half empty. Because of my pancreatitis I am a patient advisor at Michigan Medicine which allows me to be a voice for not only myself but many patients and families.

**HOW ARE YOU INVOLVED WITH NPF MICHIGAN:** I was approached a year ago by an NPF Michigan board member. I was honored to be asked to join a very important group. I currently am the fundraising chair and am excited to not only raise funds for research but to build relationships with others that are on the same pancreas journey.

**ADVICE FOR SOMEONE FACING A DIAGNOSIS:** The greatest advice I would give to family and friends when dealing with someone with a chronic condition would be to love us, listen to us, and just be there. I understand how hard it is to watch me struggle but many times all I need to know is that you’re there. As for the new patient I would say it’s okay to be mad, angry and upset. You to you!
Dietary Management
Exocrine Pancreatic Insufficiency

5TH ANNUAL
Patient and Family Centered Care for PANCREATIC DISEASES
OCTOBER 9, 2021

Amanda Lynett, MS, RDN
GI Dietitian
Division of Gastroenterology and Hepatology
Industry Relationship Disclosures
*Industry Supported Research and Outside Disclosures*

- None

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**Overview**

- Discuss the importance of nutritional screening and monitoring
- Review malabsorption, malnutrition and possible micronutrient deficiencies
- Discuss medical nutrition therapy for pancreatic diseases
- Review challenges with PERT
- Provide insight of the role of a Registered Dietitian
**Nutrition Screening and Monitoring**

Each visit:
- Discuss symptoms with provider (i.e., change in bowel habits, abdominal pain, nausea, acid reflux), changes in body weight, review adherence to medication and diet, other lifestyle factors (i.e., changes in access to food, exercise)

Annual blood tests:
- Fat soluble vitamins: vitamin A, D, E, K
- Diabetes screen: hemoglobin A1c

Periodic tests:
- Blood micronutrients: vitamin B12, copper, zinc, selenium
- Bone densitometry: DEXA every 5 years (osteopathy common)

---

**Nutrition Related Complications**

- Weight loss
- Muscle wasting (protein malnutrition)
- Edema (protein malnutrition)
- Non-traumatic bone fractures (vitamin D & K, copper)
- Night-blindness (vitamin A)
- Bleeding tendencies (vitamin K)
- Neuropathy (vitamin E, copper)
- Dermatitis & alopecia (zinc)
**Clinical Manifestations of Select Vitamin/Mineral Deficiencies**

<table>
<thead>
<tr>
<th>Vitamin A</th>
<th>Vitamin E</th>
<th>Zinc</th>
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</thead>
<tbody>
<tr>
<td>Xerophthalmia</td>
<td>Peripheral neuropathy</td>
<td>Dermatitis</td>
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<tr>
<td>Night blindness</td>
<td>Spinocerebellar ataxia</td>
<td>Alopecia</td>
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<tr>
<td>Bitot’s spots</td>
<td>Skeletal muscle atrophy</td>
<td>Diarrhea</td>
</tr>
<tr>
<td>Follicular hyperkeratosis</td>
<td>Retinopathy</td>
<td>Weight loss</td>
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<tr>
<td>Immune dysfunction</td>
<td>Anemia</td>
<td>Infection</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Vitamin D</th>
<th>Copper</th>
<th>Vitamin K</th>
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</thead>
<tbody>
<tr>
<td>Rickets</td>
<td>Neutropenia</td>
<td>Elevated prothrombin time</td>
</tr>
<tr>
<td>Bowed legs</td>
<td>Impaired bone calcification</td>
<td>Coagulopathy</td>
</tr>
<tr>
<td>Osteomalacia</td>
<td>Myelopathy</td>
<td>↓ bone health</td>
</tr>
<tr>
<td></td>
<td>Neuropathy</td>
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<tr>
<td></td>
<td>Anemia</td>
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</table>

<table>
<thead>
<tr>
<th>Malabsorption vs Malnutrition</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Malabsorption</strong> occurs when the body is unable to absorb nutrients from diets across the gastrointestinal tract.</td>
</tr>
<tr>
<td><strong>Malnutrition</strong> occurs when the body doesn’t get enough nutrients or has an imbalance of nutrients.</td>
</tr>
<tr>
<td>Increased risk of malnutrition due to:</td>
</tr>
<tr>
<td>Increased energy expenditure</td>
</tr>
<tr>
<td>Decreased PO intake</td>
</tr>
<tr>
<td>Abdominal pain</td>
</tr>
<tr>
<td>Alcohol/tobacco use</td>
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<tr>
<td>Other lifestyle factors</td>
</tr>
</tbody>
</table>

Malabsorption ➔ Malnutrition
Dietary Considerations

- Adequate calorie intake
  - Increased resting energy expenditure
  - Increase calorie needs
- Adequate dietary protein
- HYDRATION
Suggestions to Increase Calories

- Do not skip meals
- Keep food & snacks that are easily accessible (trail mix, peanut butter and crackers, canned fruit, yogurt, cottage cheese)
- Set alarms to eat around the clock
- Batch cook on weekends or days when you have more energy
- Base meal sizes/patterns around energy level or symptoms
- Choose higher-calorie drinks such as milk or smoothies
- Limit liquids at mealtimes

Suggestions to Increase Protein

- Add extra protein to meals:
  - Add hard cooked eggs to casseroles or vegetables
  - Protein powders to oatmeal/smoothies/yogurts
  - Nuts and seeds to salads, muffins, cookies
  - Dry milk powder to mashed potatoes, energy bites
Menu Ideas

BREAKFAST:
Overnight Oats: ¼ c. Greek yogurt, ½ c. rolled oats, ½ c. milk, chai seeds, protein powder, honey
Egg omelet with sauteed vegetables and cheese, roasted potatoes
Whole grain bagel topped with sliced avocado or hard boiled eggs, side of ½ cup fresh fruit

LUNCH/DINNER:
Grilled salmon or white fish with lemon, herbs, brown rice, 1 cup steamed broccoli
Whole wheat pasta with tomato sauce plus vegetables (spinach, mushrooms, peppers)
Grilled chicken kabobs with green peppers, tomatoes, mushroom, zucchini served with quinoa
Turkey burger with lettuce, tomato on a whole grain bun, sweet potato or baked potato
Homemade tuna salad on two slices of bread with 1 cup fruit

SNACKS:
Toasted bread with peanut butter and ½ banana
Cottage cheese
Greek yogurt
Premade protein shakes
Baked apple with cinnamon
Edamame
Homemade trail mix: Pretzels, almonds, walnuts, dried cranberries

Dietary Fat

- Dietary fat stimulates the pancreas to secrete digestive enzymes and may trigger pain
- 20-35% of total calories (divided between meals)
- Use of medium-chain triglycerides (MCT)
  - Doesn’t require pancreatic lipase to digest
  - Unpalatable, side effects – cramps, diarrhea, nausea
  - Limited studies
- Risk of very low-fat diets → may contribute to malnutrition
- Avoid fat restrictions unless symptoms of steatorrhea cannot be controlled
**Menu Ideas: Modify Fat as Needed**

- Enjoy a few slices of avocado on eggs, sandwiches, casseroles instead of eating a whole avocado at a meal
- Use oils such as olive oil or cooking spray instead of butter
- Try creamy nut/seed butter in place of whole nuts
- Encouraged fish rich in omega-3 fats (salmon, lake trout, tuna, herring)
- If you have a lot of difficulty with fats, try using applesauce, mashed banana or fruit puree in place of butter/oil when baking

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**Nutrition Interventions**

- Small, frequent meals (5-6/day)
- Well balanced meals that include a protein source
- Avoid unnecessary restrictions
- Limit/avoid fried, greasy foods
- Prepare meals ahead of time
- Use shakes/smoothies/softer textures as needed
**Other Interventions**

- Light exercise to stimulate appetite
- If diabetic, monitor blood sugars and consume consistent carbohydrate intake/meals throughout the day
- Abstinence to alcohol and tobacco
- Adequate sleep
- Stress management
- Individualization is key; everyone’s tolerance to foods is different

**Vitamin/Mineral Supplementation**

- Multivitamin
- Water soluble versions of fat-soluble vitamins (ADEK)
- Targeted supplements if deficiencies
**Nutrition Tips for Pancreatic Enzymes**

• Educate yourself on how to properly take

• **Meal timing:**
  1st capsule with first bite of meal/snack
  Additional capsules in the middle and/or end of meal

• Avoid grazing

• Certain foods may not require enzymes
  (i.e. juice, hard candy, slice of white bread)

• Monitor your symptoms before and after starting pancreatic enzymes; notify provider

---

**Role of GI Dietitian**

• Screen and monitor for malnutrition

• Gather other pertinent background information

• Nutrition interventions that are individualized (dietary modifications, lifestyle modifications)

• Aids in managing GI symptoms (loss of appetite, abdominal pain, bone health)
Resources

• For those with EPI: Exocrine Pancreatic Insufficiency (EPI) Videos (identifyepi.com)
• Chronic Pancreatitis Cookbook by Sally Sampson: NPF-CHRONIC-PANCREATITIS-COOKBOOK_081916.pdf (pancreasfoundation.org)
• Pancreas Foundation Nutrition Resources: Nutrition Advice & Recipes - The National Pancreas Foundation

Thank you
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**Genetic Causes of Pancreatic Diseases**
*Case-Based Discussions*

**5TH ANNUAL**
Patient and Family Centered Care for
**PANCREATIC DISEASES**
OCTOBER 9, 2021

Andrea M. Murad, MS, CGC  
Lead Genetic Counselor  
Division of Genetic Medicine

Tannaz Guivatchian, MD  
Clinical Assistant Professor  
Department of Internal Medicine
Industry Relationship Disclosures

Industry Supported Research and Outside Disclosures

- Andrea Murad is a paid consultant for Concert Genetics
- Tannaz Guivatchian has no disclosures to report

Overview

- Case examples
- Genetics 101
- What is Genetic Counseling?
- Gathering a family history
- Genetic testing process
- What does having an inherited cancer syndrome mean?
Case Examples

Chronic Pancreatitis
Differential: What are the Possibilities

- Environmental: smoking, alcohol
- Anatomic factors, Trauma
- Chronic Medical Conditions: Diabetes, Celiac Disease, Autoimmune
- Hypertriglyceridemia
- Recurrent acute pancreatitis of any etiology
- Genetic/Hereditary
- Idiopathic: Early onset (age 20) vs late onset

Genetic Causes of Chronic Pancreatitis

- PRSS1: can be associated with up to a 50% lifetime risk of developing pancreatic cancer
- SPINK1
- CFTR
- CASR
- CTRC
Case #1

• 36-year-old woman with chronic pancreatitis
• Pancreatitis History
  – Age 26 (2007): First episode
    • Total of 10 hospitalizations
  – Age 27 (2008): diagnosed with chronic pancreatitis by EUS imaging
    • started pancreatic enzyme supplements
  – Age 35 (2016): MRI and CT imaging showing atrophic pancreas

Case #1 Continued

• Additional Medical History:
  – Diabetes
  – Hypercholesterolemia first diagnosed at age 27, total cholesterol >300

• Nonsmoker, rare alcohol use
Case #1 Family History

- Mother with one episode of pancreatitis, no cancer history
- Maternal aunt with chronic pancreatitis, no cancer history
- Sister with chronic pancreatitis
Case #1 Genetic Testing Results

Found to have a pathogenic variant in the SPINK1* gene
- 6-12 fold increased risk of chronic pancreatitis
- Possible increased risk of pancreatic cancer: recommend annual pancreatic cancer screening if there is family history of pancreatic cancer
- Testing of additional family members
  - If positive, then avoid high risk behaviors such as alcohol and tobacco use

* SPINK1, serine peptidase inhibitor Kazal type 1

Pancreatic Cancer
Pancreatic Cancer Risk Factors

**Definite Risk Factors**
- Age
- Smoking
- Hereditary pancreatitis
- Other familial syndromes (10%)
- Diabetes (particularly recent dx)
- Obesity
- Non-O blood group
- Pancreatic cysts (e.g. IPMN)
- Chronic pancreatitis (inflammation)

**Possible**
- Diet: Fat, Dairy, Red meat
- Alcohol
- Chemicals: Benzidine, beta-naphthylamine

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**Hereditary Breast Ovarian Syndromes:**
- BRCA 1 or 2
- PALB2
- ATM

**Familial Melanoma**
- CDKN2A

**Peutz Jeghers Syndrome**
- STK11

**Lynch Syndrome:**
- MLH1, MSH2, MSH6, PMS2

**Hereditary Pancreatitis**
- PRSS1, SPINK1, others
Case #2

- 34-year-old gentleman with pancreatic adenocarcinoma
- Healthy
- No history of pancreatitis, diabetes, or hypertriglyceridemia
- No personal history of tobacco use or heavy alcohol use

Case #2 Family History

- Mother: pancreatic cancer at 51
- Maternal uncle: pancreatic cancer at 29, passed away at 39
- Maternal grandmother: breast cancer in her 60s, still living
- Sister: jaw cancer at 19, passed away at 24
Case #2: Genetic Testing Results

CDKN2A* pathogenic variant: Familial Melanoma

- Associated with a >15% lifetime risk of pancreatic cancer
- Risk of melanoma 28-76%, recommend annual dermatology visit
- Annual pancreatic cancer screening
- Recommend testing for family members

*CDKN2A, cyclin-dependent kinase inhibitor 2A
Genetics 101
Back to high school biology class

I’LL CLIMB UP THIS STRAND OF DNA TO SEE WHERE LIFE TAKES ME.

Chromosome to Gene to Protein

Cell
Chromosomes: Each chromosome is composed of one long continuous DNA molecule.

Gene: A gene is a segment of DNA that encodes a protein product.

Protein: A protein is a complex organic compound composed of hundreds or thousands of amino acids.

DNA
Nucleotides:
- Adenine
- Thymine
- Guanine
- Cytosine
What is genetic counseling?

Who are Genetic Counselors?

• Healthcare professionals who have specialized education in genetics and counseling

• Provide personalized guidance to patients making decisions about their genetic health
  – Often work as part of a team along side other healthcare professionals

• Interpret genetic test results and guide and support patients seeking more information about such things as:
  – How inherited diseases and conditions might affect them or their families
  – How family and medical histories may impact the chance of disease occurrence or recurrence
  – Which genetic tests may or may not be right for them
  – What those tests may or may not tell
  – How to make the most informed choices about healthcare conditions.
What is involved in a genetic counseling visit?

• Visits typically last 30-75 min, depending on the reason for referral

• Your genetic counselor will:
  – Explore your family health history
  – Discuss the reason for the referral
  – Talk about decisions that may need to be made
  – Help you understand what tests are available, what those tests may show, and provide guidance to help you decide whether to choose testing
  – Provide guidance and emotional and support as you decide what to do

Gathering a Family history
Family health history

- Medical and health information about a person & blood relatives
- Give clues to conditions that may run in a family
- Helps identify individuals who are at an increased risk of developing those conditions

Important information to collect

- For both maternal and paternal relatives try to collect:
  - Age or date of birth (estimate if exact age unknown)
  - If deceased, age of death (estimate if exact age unknown) and cause of death
- Cancer history
  - Age at diagnosis?
  - What type of cancer or where did their cancer originate?
  - Did any family members undergo genetic testing?
- Pay special attention to conditions that occur in more than one person
- Make note of any lifestyle/environmental exposures (e.g. smoking history)
- Ethnicity on both maternal and paternal sides of the family
- Make note of any related family members who have married each other
Genetic testing

What Does the Actual “Testing” Involve?

- Typical gene: GAGATC
  - Sequencing finds spelling errors: GAGATA
  - Deletion/duplication analysis finds missing or extra pieces: GAGAT, GAGATCC
Genetic test results

- **Positive (Pathogenic or likely pathogenic variant/mutation)**
  - Your blood shows a change that is known to be associated with a particular condition
    - Often provides a diagnosis
    - Can help explain the cause of a condition and/or symptoms
    - Can also identify individuals who have a genetic pre-disposition to a certain condition

- **Negative**
  - This DOES NOT mean “not genetic”
    - No currently known changes associated with a condition were identified in the genes tested
    - Undiscovered genes might contribute to risk, but have not been discovered and therefore were not tested

- **Variant of Unknown Significance (VUS)**
  - Your blood shows a change in a gene for which there is not enough information to determine if it is benign or if it is associated with increased risk

Insurance Coverage/Cost

- Some insurance will cover genetic testing, and some will not
  - Will also be subject to deductibles and co-insurance

- Many labs will perform a benefits investigation to determine estimated out of pocket cost and will contact you if >$100

- Many labs offer financial assistance and self-pay prices than can be lower than going through insurance.
  - Certain labs can offer genetic testing for $250 out of pocket
What does this mean for me?

- Health Management/Surveillance
  - Specific guidelines or screening recommendations for your medical management
  - Find a healthcare provider who is familiar with your condition and make them your point person
    - High Risk Cancer Clinics
    - Specialist (e.g. Gastroenterologist, OB/Gyn, Geneticist, etc.)
    - A genetic counselor may be able to help you find a provider if you do not have one

- Become an expert in your condition
  - Management resources
    - National Comprehensive Cancer Network guidelines (www.nccn.org)
    - www.cancernet.org

- Keep a chart or binder to keep track of your medical management recommendations
- Your specific management plan may be different than others with the same condition
- Each person is an individual and their medical management should be too

What does this mean for me?

- Take care of you
  - Emotional health
    - Am I the only one?
      - Support groups
      - Patient advocacy groups
    - I have so many big decisions to make and I feel so alone
      - Social workers
      - Genetic Counselors
      - Psychologist/Psychiatrist
  - Other things you can do to reduce cancer risk
    - Eat healthy and keep an active lifestyle
    - Do not smoke
    - Drink alcohol in moderation
What does this mean for my family?

- When a genetic condition is identified in a family, other blood relatives may be at risk of inherited this same condition
  - First-degree relatives (children, siblings and parents) have a 50% chance
- Genetic testing can help determine which other family members (if any) inherited the genetic variant and may be at risk for the condition
  - This will allow them to undergo appropriate screening which can reduce their cancer risk

Things to remember

- Support is available for
  - Dealing with your own diagnosis and medical management
  - To help you communicate genetic information with your family members
- We are a community
  - We can help you get the information you need
- Don’t give up!
  - Genetic testing can identify which relative need increased cancer screening, aimed at early detection of cancer and saving lives!
PARTNERS

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GI Genetics Evaluation for Pancreatic Diseases

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Elena M. Stoffel MD MPH
Associate Professor of Internal Medicine
Division of Gastroenterology
Industry Relationship Disclosures

*Industry Supported Research and Outside Disclosures*

- None

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**Precision Medicine**

“An emerging approach for disease treatment and prevention that takes into account *individual variability* in genes, environment, and lifestyle for each person.”

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*National Institutes of Health*

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*What Treatment is best for ME?*
Objectives

• Pancreatic disease and genetics: how does this impact
  – Screening
  – Treatment
  – Prevention

Case Example

• “My sister was just diagnosed with pancreatic cancer.
  – What (if anything) do we need to do?”
Genetics and Cancer Risk

- 70-80% - Sporadic
- 10-20% - Familial
- 5-10% - Hereditary Cancer Syndromes

Genetic Predisposition to Cancer

- **Colorectal Cancer**
  - 1 in 300
  - Genes: APC, MUTYH, MLH1, MSH2, MSH6, PMS2, EPCAM

- **Breast/Ovarian Cancer**
  - 1 in 100
  - Genes: BRCA1, BRCA2, PALB2

- **Pancreatic Cancer**
  - Genes: ATM, CHEK2, TP53, CDKN2A

- Other Genetic Syndromes:
  - APC, MUTYH, MLH1, MSH2, MSH6, PMS2, EPCAM
  - PTEN, SMAD4, BMPR1A, STR11

- Darker shading represents higher penetrance.

- Size approximates population prevalence.
Families with Genetic Risk are Underdiagnosed

- 1 in 300 people carry gene changes associated with Hereditary Breast Ovarian Cancer Syndrome (BRCA)
- 1 in 300 people carry gene changes associated with Lynch Syndrome
- 1 in 100 people carry changes in ATM gene
- 1 in 31 people carry changes in CFTR gene
- How do we identify and intervene early?

Red Flags for Possible Hereditary Syndromes

- Young ages at diagnosis
- Multiple primary cancers in a single individual
- Multiple family members affected with same/related conditions
  - Breast and ovarian cancers
  - Colon and endometrial cancers
  - Young breast and prostate cancers
  - Pancreatic cancers
  - Pancreatitis
“My sister was recently diagnosed with pancreatic cancer -- what (if anything) should my family do?”

Genetic testing in sister revealed a pathogenic variant in BRCA2—This information changes management AND makes predictive testing available to other family members!

BRCA, breast cancer gene

Why is a genetic diagnosis important?

• Use of specific cancer therapies that target the cause of the cancer
  – PARP inhibitor therapy for BRCA mutated tumors can improve survival

BRCA, breast cancer gene
PARP, Poly (ADP-ribose) polymerase
Why is a genetic diagnosis important?

- Use of specific cancer therapies that target the cause of the cancer
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- Screening for other related cancer types
  - Specialized breast cancer screening for carriers of BRCA1 or BRCA2
  - Screening for pancreatic cancer

BRCA, breast cancer gene
PARP, Poly (ADP-ribose) polymerase

Screening for Pancreatic Cancer

Endoscopic Ultrasound (EUS)
MRI/MRCP
Early Detection/Prevention

- Who should be screened for pancreatic cancer?
  - Individuals who carry specific germline gene changes associated with high risk
    - CDKN2A, STK11
  - Individuals who carry specific germline gene changes AND have a family history of a close relative with pancreatic cancer
    - BRCA1, BRCA2, ATM, MLH1, MSH2, MSH6, PMS2
  - Individuals who have 2 or more close relatives with pancreatic cancer
  - Individuals with hereditary pancreatitis

Genetics in the News

*Slide courtesy of S. Roberts PhD*
Who should undergo clinical genetic testing for pancreatic disease?

**Pancreatic Cancer**
- All individuals with a diagnosis of pancreatic cancer (Genetic diagnosis in 1 in 20)
- Members of families in which there is an identified genetic disease causing germline gene variant
- Individuals who meet criteria for familial pancreatic cancer
- Close relatives (siblings, children, parents) if the pancreatic cancer patient was not able to undergo genetic testing

**Pancreatitis**
- Individuals who have recurrent acute pancreatitis AND family history of close relative(s) with pancreatitis
- Children and young adults with unexplained recurrent pancreatitis
- *PRSS1, SPINK1, CTRC, CASR, CFTR*
What Influences whether a patient gets genetic testing?

Adaptation of the Integrative Model of Behavior

Find a genetic specialist near you:
Michigan Department of Health and Human Services Cancer GenomicsMichigan.gov/mdhhs
Factors that Impact Your Risk for Disease

- Genetics
- Inflammation
- Microbiome
- Vitamin D
- Diet
- Smoking
- Health Behaviors
- Environment
- Screening
Summary

• Talk to your medical team about your family health history
  – Does this meet criteria for genetic testing?

• Genetics ≠ destiny, but can provide important info for care
  – Change treatments
  – Change behaviors

Thank you!
U-M Cancer Genetics/Adult Medical Genetics Clinics
estoffel@med.umich.edu
5TH ANNUAL
Patient and Family Centered Care for
PANCREATIC DISEASES
OCTOBER 9, 2021

11:30 am  Welcome
Matthew DiMagno, MD - Course Director

11:40  MM Comprehensive Pancreas Program Updates
Richard Kwon, MD

11:50  NPF Michigan Chapter Updates
Robin Winke, LMSW

Part I. Maldigestion

12:00 pm  Clinical Problem - Maldigestion
Erik-Jan Wamsteker, MD

12:05  Patient Testimony

12:15  Keynote Presentation: Dietary Management
Amanda Lynett, MS, RDN

Panel Discussion

CLOSING REMARKS

Part II. Genetics

1:10  Genetic Causes of Pancreatic Diseases –
Case-Based Discussions
Andrea Murad, MS, CGC
Tannaz Guivatchian, MD

1:35  Keynote Presentation: GI Genetics Evaluation
for Pancreatic Diseases
Elena Stoffel, MD, MPH

Panel Discussion

THANK YOU and REMINDER

• Please respond to pre- and post-event communications
  ❑ Complete 9 true/false questions (pre- and post-event)
    -> provides a measure of learning and effectiveness of speakers
    -> eligible for a drawing for prizes, for completing pre- and post-event
  ❑ Suggest topics for next years program to meet your needs

• Receive email with link to course syllabus and video
  ❑ 5th Annual Event (Oct 9, 2021): available in 2 weeks
  ❑ 4th Annual Event (Oct 17, 2020): SEE here
NOV 13 2021
PANC WALK

6TH ANNUAL MICHIGAN NATIONAL PANCREAS FOUNDATION FUNDRAISING WALK TO HELP SUPPORT AND EDUCATE PATIENTS AND FAMILIES WITH PANCREATIC DISORDERS

To register and/or donate:
https://give.pancreasfoundation.org/ge/pancwalk

Mark Your Calendar
October 2022
(1st or 22nd)

6TH ANNUAL
Patient and Family Centered Care for
PANCREATIC DISEASES

Saturday, OCTOBER 2022 (1st or 22nd)
11:30 am – 2:30 pm
The Inn at St Johns, Plymouth, Michigan