



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 <i>Matthew DiMagno, MD - Course Director</i>	12:30 pm	Panel Discussion
11:40	MM Comprehensive Pancreas Program Updates <i>Richard Kwon, MD</i>	12:55	Break
11:50	NPF Michigan Chapter Updates <i>Robin Winke, LMSW</i>	1:10	Genetic Causes of Pancreatic Diseases - Case-Based Discussions <i>Elena Stoffel, MD, MPH</i> <i>Tannaz Guivatchian, MD</i> <i>Andrea Murad, CGC</i>
12:00 pm	Clinical Problem - Maldigestion <i>Erik-Jan Wamsteker, MD</i>	1:35	Keynote: GI Genetics Clinic <i>Elena Stoffel, MD</i>
12:05	Patient Testimony	2:00	Panel Discussion
12:15	Keynote: Dietary Management <i>Amanda Lynett, MS, RD</i>	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/xo12W>

Event Partners: **AbbVie, Chiesi, Nestle and Vivus**



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



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Introduction and Updates

10. Introduction – 5th Annual Patient & Family Centered Care for Pancreatic Diseases <i>Matthew DiMagno, MD - Course Director (Medical Director, NPF Michigan Chapter)</i>	14-18
11. Michigan Medicine Comprehensive Pancreas Program Updates <i>Richard Kwon, MD, MS (Board Member, NPF Michigan Chapter)</i>	19-28
12. National Pancreas Foundation (NPF) Michigan Chapter Updates <i>Robin Winke, LMSW (Chair, NPF Michigan Chapter)</i>	29-35

Part I. Maldigestion

13. Clinical Problem – Maldigestion <i>Erik-Jan Wamsteker, MD (Board Member, NPF Michigan Chapter)</i>	36-40
14. Patient Testimony <i>Georgiann Z (Board Member, NPF Michigan Chapter)</i>	41-42
15. Keynote Presentation: Dietary Management <i>Amanda Lynett, MS, RD</i>	43-51
16. Panel Discussion	

Part II. Genetics

17. Genetic Causes of Pancreatic Diseases – Case-Based Discussions <i>Andrea Murad, MS, CGC</i> <i>Tannaz Guivatchian, MD</i>	52-71
18. Keynote Presentation: GI Genetics Evaluation for Pancreatic Diseases <i>Elena Stoffel, MD, MPH</i>	72-83
19. Panel Discussion	

Closing Remarks

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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



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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*



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***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).



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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



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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, photoperiod sensitive genic male sterility

PRSS1, serine protease 1 (cationic trypsinogen)

PsyD, Doctor of Psychology

QOL, quality of life

RD, registered dietician

REE, resting energy expenditure



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SIBO, small intestinal bacterial overgrowth

SPINK1, small intestinal bacterial overgrowth

STK11, serine/threonine kinase 11

THC, tetrahydrocannabinol

VUS, variant of unknown significance



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Weblinks

Michigan Medicine, *Comprehensive Pancreas Program – Gastroenterology*

- https://medicine.umich.edu/dept/intmed/divisions/gastroenterology/hepatology/programs/comprehensive_pancreas_program
- Appointments: 888 229 7408 (www.UofMHealth.org/gi)

To donate

- <https://michmed.org/xo12W>



Michigan Medicine, *Pancreatic Cancer Clinic – Cancer Center*

- https://www.rogelcancercenter.org/pancreatic_cancer/clinic
- <https://pancreas.med.umich.edu/>



National Pancreas Foundation, Michigan Chapter

Home page – board, educational events, support group meeting

- 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>



National Pancreas Foundation (NPF)

Home page

- <https://pancreasfoundation.org/>

NPF Centers of Excellence

- https://pancreasfoundation.org/npf_centers_info/

State chapters

- https://pancreasfoundation.org/state_chapters/

About the pancreas

- https://pancreasfoundation.org/patient_information/about_the_pancreas/

Animated pancreas patient

- https://pancreasfoundation.org/patient_information/animated_pancreas_patient/





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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 <u>requires</u> multidisciplinary expertise in pancreatic diseases__	True	False
2. Winke	The NPF Michigan chapter <u>has</u> support group meetings once per month_____	True	False
3. Wamsteker	Severe pancreatic insufficiency (maldigestion) <u>is treated</u> with pancreatic enzymes__	True	False
4. Patient	Patient family involvement <u>does not</u> 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 <u>is only</u> for patients with a family history_____	True	False
8. Murad	Genetic testing for pancreatic cancer <u>is most often performed</u> by blood testing__	True	False
9. Stoffel	Genetic counseling <u>includes</u> 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: _____



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

Please evaluate the overall quality of program below

This event increased my knowledge	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
This event was valuable to me	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
I will attend next year's event?	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

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: _____



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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



**PANC
WALK**

NOVEMBER 13TH
2021

PAINT CREEK TRAIL

11:30 AM - 2:30 PM

FAMILY AND PET
FRIENDLY!

DONATE HERE:



Check us out online:
Pancreasfoundation.org

Find us on facebook.com/michiganpancreasfoundation.org

REGISTER

<https://give.pancreasfoundation.org/ge/pancwalk>



**NOV 13 2021
PANC WALK**

1ST 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>



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**Patient and Family Centered Care for
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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 1:10

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

12:05 **Patient Testimony** 1:35

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

Panel Discussion

Part II. Genetics

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

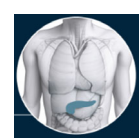
**Keynote Presentation: GI Genetics Evaluation
 for Pancreatic Diseases**
Elena Stoffel, MD, MPH

Panel Discussion



Welcome

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



Live Webinar Broadcast University of Michigan Medical Campus



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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



BRIEF ANNOUNCEMENTS

- **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 



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BRIEF ANNOUNCEMENTS

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



Digestive and Liver Health

Why Choose Michigan

Our Care Team

Your Digestive System

Education Videos

Make an Appointment

Conditions and Procedures

Pancreatic Disorders

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

Patient Portal Login

Related Links

4th Annual Patient Ed Event (Video)

4th Annual Patient Ed Event (Slides)



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





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



Board Members

*Vicky Vincent, Board Secretary

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Part I. Maldigestion

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Amanda Lynett, MS, RDN

Panel Discussion

1:10

Part II. Genetics

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

1:35

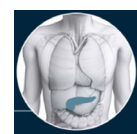
**Keynote Presentation: GI Genetics Evaluation
 for Pancreatic Diseases**
Elena Stoffel, MD, MPH

Panel Discussion



MM Comprehensive Pancreas Program Updates

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Richard Kwon, MD
 Associate Professor of Internal Medicine
 Board Member, NPF Michigan Chapter



Industry Relationship Disclosures

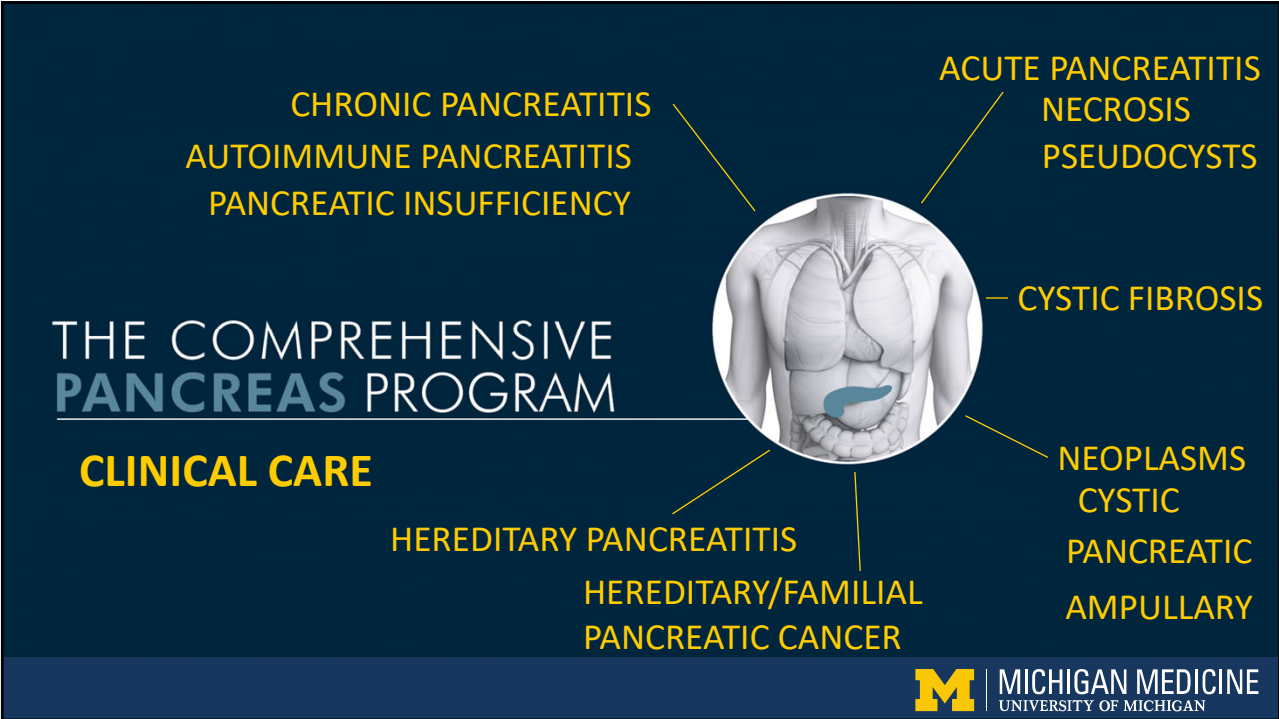
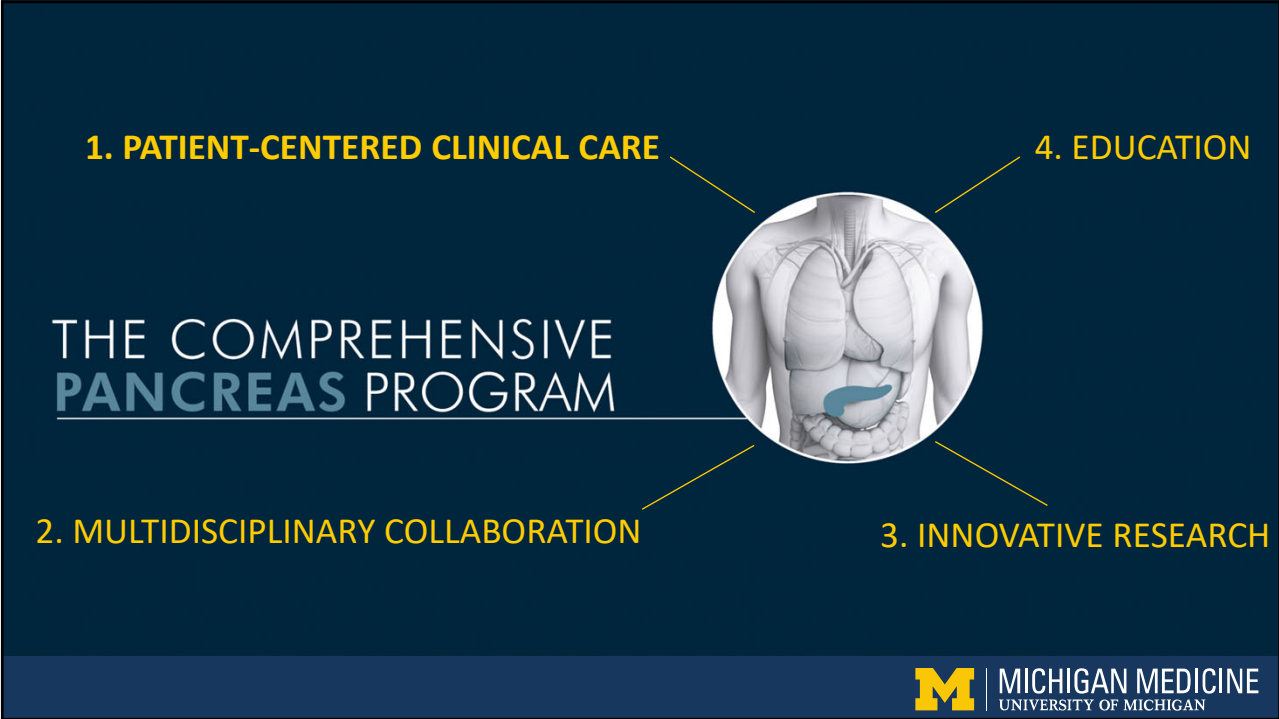
Industry Supported Research and Outside Disclosures

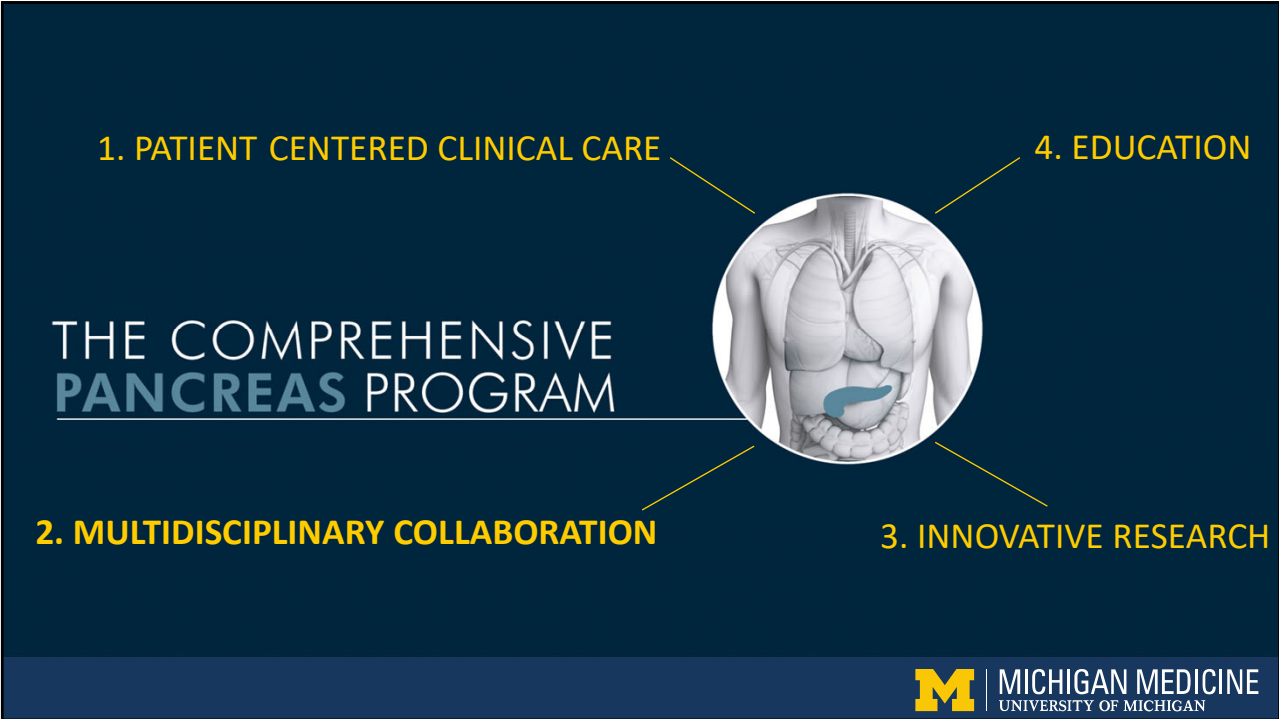
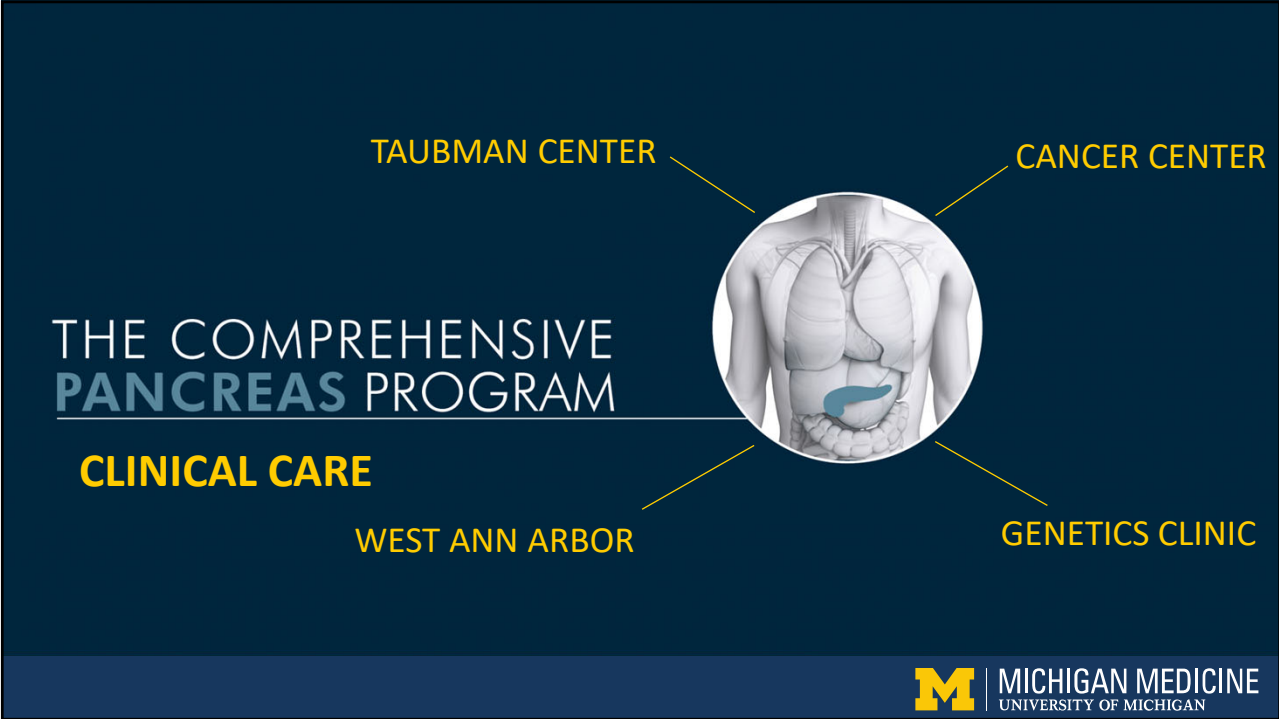
- Abbvie (research)

THE COMPREHENSIVE
PANCREAS PROGRAM

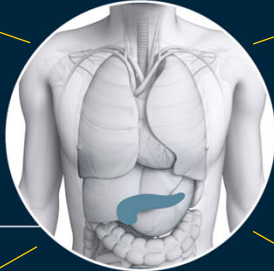
ESTABLISHED 2018







GASTROENTEROLOGY



SURGERY **RADIOLOGY**

PATHOLOGY

ONCOLOGY

ENDOCRINOLOGY

PAIN & BEHAVIOR SPECIALISTS

THE COMPREHENSIVE PANCREAS PROGRAM

MULTIDISCIPLINARY CARE

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UNIVERSITY OF MICHIGAN

GASTROENTEROLOGY



SURGERY **RADIOLOGY**

THE COMPREHENSIVE PANCREAS PROGRAM

BENIGN PANCREAS CONFERENCE

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GASTROENTEROLOGY

SURGERY

RADIOLOGY

PATHOLOGY

ONCOLOGY

**THE COMPREHENSIVE
PANCREAS PROGRAM**

MULTIDISCIPLINARY TUMOR BOARD

M | MICHIGAN MEDICINE
UNIVERSITY OF MICHIGAN

1. PATIENT CENTERED CLINICAL CARE

4. EDUCATION

**THE COMPREHENSIVE
PANCREAS PROGRAM**

2. MULTIDISCIPLINARY COLLABORATION

3. INNOVATIVE RESEARCH

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CHRONIC PANCREATITIS
PANCREATIC INSUFFICIENCY

ACUTE PANCREATITIS
NECROSIS
PSEUDOCYSTS

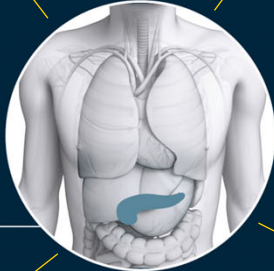
— CYSTIC FIBROSIS

NEOPLASMS
CYSTIC
PANCREATIC

HEREDITARY/FAMILIAL
PANCREATIC CANCER

**THE COMPREHENSIVE
PANCREAS PROGRAM**

INNOVATIVE RESEARCH



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UNIVERSITY OF MICHIGAN

* Study coordinator: Sarah Volk
phone: 734-936-5704
email: stomanic@med.umich.edu

**Cancer AnswerLine: 800-865-1125

ACUTE PANCREATITIS

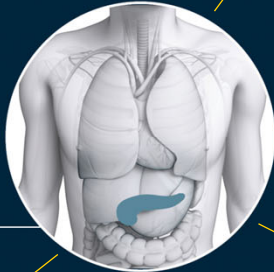
— CYSTIC FIBROSIS

NEOPLASMS
CYSTIC*
PANCREATIC**

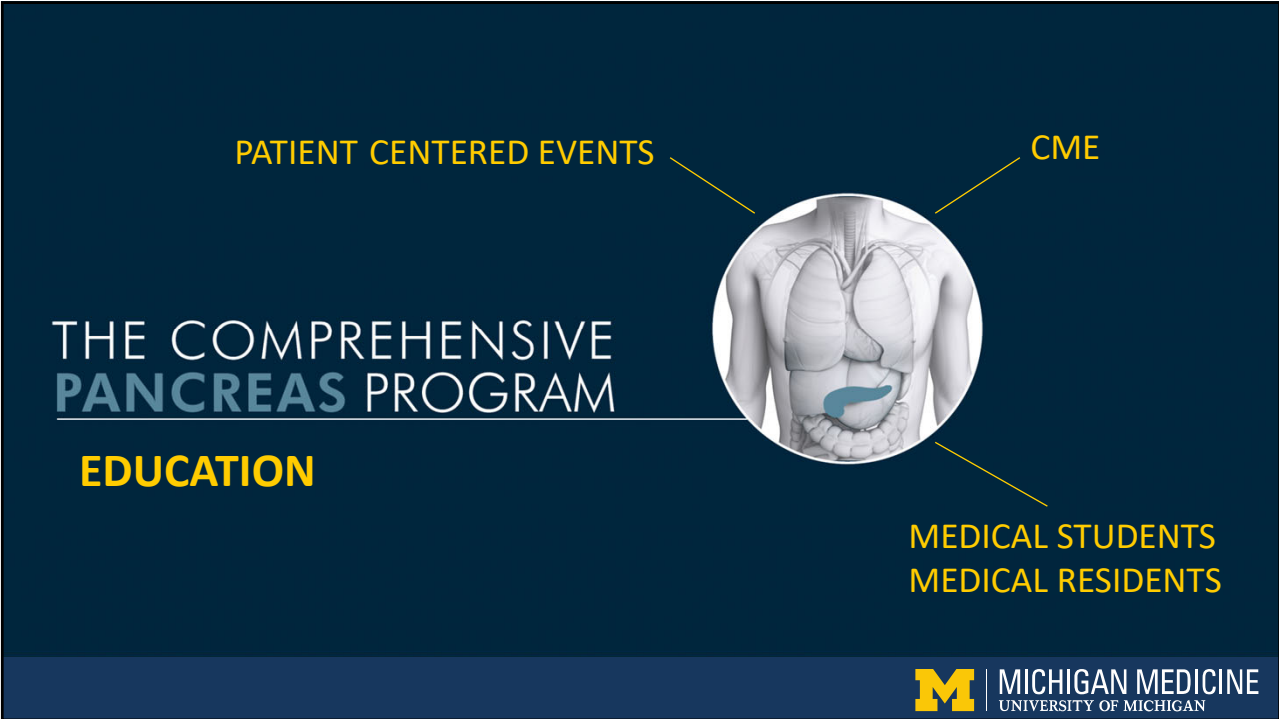
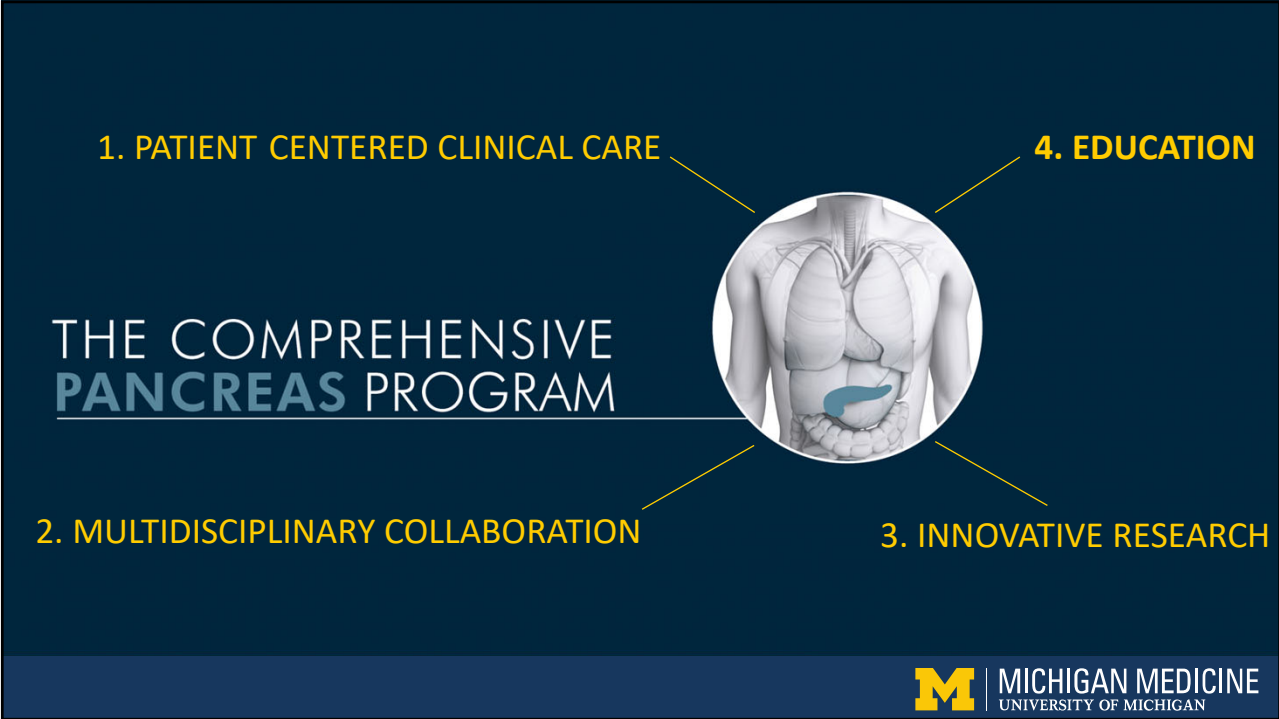
HEREDITARY/FAMILIAL*
PANCREATIC CANCER

**THE COMPREHENSIVE
PANCREAS PROGRAM**

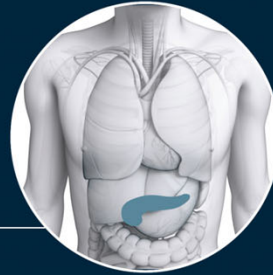
INNOVATIVE RESEARCH



M | MICHIGAN MEDICINE
UNIVERSITY OF MICHIGAN



THE COMPREHENSIVE PANCREAS PROGRAM



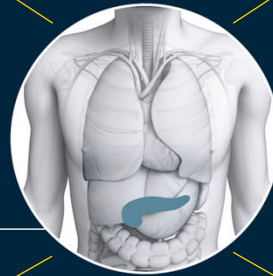
FIRST IN MICHIGAN



1. PATIENT CENTERED CLINICAL CARE

4. EDUCATION

THE COMPREHENSIVE PANCREAS PROGRAM

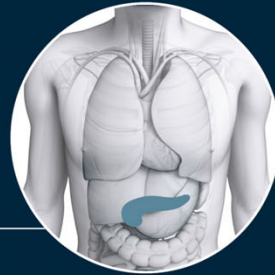


2. MULTIDISCIPLINARY COLLABORATION

3. INNOVATIVE RESEARCH



THE COMPREHENSIVE
PANCREAS PROGRAM



THANK YOU

5TH ANNUAL
**Patient and Family Centered Care for
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**Genetic Causes of Pancreatic Diseases –
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Elena Stoffel, MD, MPH

Panel Discussion



**NATIONAL PANCREAS
 FOUNDATION MICHIGAN CHAPTER**

5TH ANNUAL
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 OCTOBER 9, 2021

Robin Winke, LMSW
 Chair, National Pancreas Foundation Michigan Chapter

NATIONAL PANCREAS FOUNDATION MISSION

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



The
National Pancreas
Foundation

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. DiMugno, 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





MISSION: Provide hope for those suffering from pancreatitis and pancreatic cancer through funding cutting edge research, advocating for new therapies, and providing support and education for patients, caregivers, and providers

MISSION

- Provide hope for those suffering from pancreatitis and pancreatic cancer through funding cutting edge research, advocating for new therapies, and providing support and education for patients, caregivers, and providers

HISTORY OF SUCCESS

- Only foundation dedicated to patients suffering from all forms of pancreas disease: pediatric pancreatitis, acute & chronic pancreatitis, pancreatic cancer
- Grants made directly to researchers seeking to resolve challenging medical problems of pancreatic diseases
- Grant proposal reviewed by scientific review committee
- Over \$4 million awarded for 127 groundbreaking projects
- Collaboration with NIH, Department of Defense, and others

STATE CHAPTERS

- Established to network with physicians; patients; family members, and caregivers to provide support and encouragement
- Volunteers understand needs of their communities and promote patient, public, & professional education

MICHIGAN

State Chapter-since 2017

<https://pancreasfoundation.org/state-chapters/michigan/>

Chair
Robin Winkle, LMSW

Medical Director:
Matthew DiMugno, MD

Board
Clifford S. Cho, FACS
Richard Kwon, MD
Lance Judd
Vicky L. Vincenz, CAP
Erik-Jan Wanscher, MD
Derrick Winkle, ATA, ATP, MBA
Georganna Ziegler
Megan Mori, PVC

NPF Centers

Michigan Medicine, Ann Arbor - 1st in MI
Walter Michigan Cancer Center, Kalamazoo

EDUCATION

NPF Animated Pancreas Patient

<http://www.animatedpancreaspatient.com/en-pancreas/home>

- Resource for patients
- Expert advice to help discuss management issues with your provider
- Easy-to-understand animations with audio narration, video explanations, patient interviews, slide shows, and downloadable information



2021 Michigan Chapter

2020 Event	Diabetes and Pancreatic Pain (virtual event)	256 registrants; 40 states, 5 countries
2019 Event	Malnutrition and Pancreatic Cancer	75 attendees; 95% planned to return
2018 Event	Complex Care and Pancreatic Pain	80 attendees; 93% planned to return
2017 Event	Patient/Family Centered Care and NPF Centers	35 attendees; 87% planned to return

GRANT FUNDING & REGISTRY

2021 Grants Awarded by NPF

CANCER

- Targeting Asparagine Metabolism in Pancreatic Cancer

PANCREATITIS

- Incorporating Ffoculoscopic Ultrasound and Fibroscopy towards improving outcomes of Pediatric Pancreatitis Management
- Repurposing responses of ductal progenitor cells in a genetic and inducible injury model for severe acute and chronic pancreatitis

NPF National Patient Registry

- Determine factors driving prognosis & care quality in those with pancreatic disease
- Guide: Improve life quality and outcomes

SUPPORT GROUP

2021 Michigan Chapter

FUNDRAISING

2021 Event - Michigan Chapter

Past Events - Michigan Chapter

Pancreatic Diseases Educational Event
Ice at St. Joe's, Plymouth, MI
10/19/2019: Funds Raised: \$245

NPF Michigan Ice Cream Fundraiser
Shree Dairy, Farmington, MI
08/12/2018: Funds Raised: \$750
07/14/2019: Funds Raised: \$450

Annual Dine in & Take Cancer Out
The Marini, 311 S Main St, Royal Oak, MI
Partners: Dr. Ramesh Kumar Foundation
And the Bekker Testel Family
02/16/2019: Funds Raised: \$5,000
02/15/2020: Funds Raised: \$3,500

• To Donate: <https://give.pancreasfoundation.org/give/pancreas/>
• Goal: to support educational, research and patient advocacy
• NPF Michigan Partners: AbiVie, Chesi, Neelke, Vivus, Michigan Medicine

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!

ICE CREAM SOCIALS

PARTNERING WITH OTHER FOUNDATIONS

PANCREASBOWL

FB CHALLENGES

ANNUAL PANC WALK



PANC WALK

NOVEMBER 13TH
2021

PAINT CREEK TRAIL

11:30 AM - 2:30 PM

FAMILY AND PET
FRIENDLY!

DONATE HERE:



Check us out online:
Pancreasfoundation.org

Find us on facebook.com/michiganpancreasfoundation.org

REGISTER

<https://give.pancreasfoundation.org/ge/pancwalk>



NOV 13 2021 PANC WALK

1ST 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>





Volunteer
Opportunity
Host Support
Groups
Fundraising
Board members

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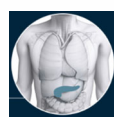
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Panel Discussion



Maldigestion – Clinical Problem

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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 (ie. 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

Maldigestion – Patient Testimonial

12:00 pm	Clinical Problem - Maldigestion <i>Erik-Jan Wamsteker, MD</i>
12:05	Patient Testimony <i>Recorded Interview</i>
12:15	Keynote: Dietary Management <i>Amanda Lynett, MS, RDN</i>
12:30	Panel Discussion

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Maldigestion – Patient Testimony

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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!

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Dietary Management

Exocrine Pancreatic Insufficiency

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Amanda Lynett, MS, RDN
 GI Dietitian
 Division of Gastroenterology and Hepatology



Industry Relationship Disclosures

Industry Supported Research and Outside Disclosures

- None

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

Vitamin A	Xerophthalmia <i>Night blindness</i> Bitot's spots Follicular hyperkeratosis Immune dysfunction	Vitamin E	<i>Peripheral neuropathy</i> Spinocerebellar ataxia Skeletal muscle atrophy Retinopathy Anemia	Zinc	<i>Dermatitis</i> Alopecia Diarrhea Weight loss Infection Hypogonadism
Vitamin D	Rickets Bowed legs <i>Osteomalacia</i>	Copper	Neutropenia <i>Impaired bone calcification</i> Myelopathy <i>Neuropathy</i> Anemia		
Vitamin K	Elevated prothrombin time <i>Coagulopathy</i> ↓ <i>bone health</i>				

Malabsorption vs Malnutrition

- **Malabsorption** occurs when the body is unable to absorb nutrients from diets across the gastrointestinal tract
- **Malnutrition** occurs when the body doesn't get enough nutrients or has an imbalance of nutrients
- Increased risk of malnutrition due to:

Increased
energy
expenditure

Decreased PO
intake

Abdominal pain

Alcohol/tobacco
use

Other lifestyle
factors

Malabsorption → Malnutrition

Medical Nutrition Therapy

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



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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



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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

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

Table 1 Current Food and Drug Administration (FDA) approved pancreatic enzyme replacement therapies (PERTs)

Brand	Units of lipase
Creon	3000; 6000; 12,000; 24,000; 36,000
Zenpep	3000; 5000; 10,000; 15,000; 20,000; 25,000
Pancreaze	4200; 10,500; 16,800; 21,000
Ultresa	13,800; 20,700; 23,000
Viokase	10,440; 20,880 (requires acid suppression)
Pertzye	8000; 16,000

- 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)

<i>What's for Dinner?</i>		
DAY OF THE WEEK	MAIN DISH	SHOPPING LIST
<i>Sunday</i>		
<i>Monday</i>		
<i>Tuesday</i>		
<i>Wednesday</i>		
<i>Thursday</i>		
<i>Friday</i>		
<i>Saturday</i>		
<i>Misc.</i>		

Resources

- For those with EPI: [Exocrine Pancreatic Insufficiency \(EPI\) Videos \(identifyepi.com\)](https://www.identifyepi.com)
- Chronic Pancreatitis Cookbook by Sally Sampson: [NPF-CHRONIC-PANCREATITIS-COOKBOOK_081916.pdf \(pancreasfoundation.org\)](https://pancreasfoundation.org/PANCREATITIS-COOKBOOK_081916.pdf)
- Recipes for Pancreatic Cancer: <https://www.pancan.org/facing-pancreatic-cancer/living-with-pancreatic-cancer/diet-and-nutrition/cooking-comfort-care/>
- Pancreas Foundation Nutrition Resources: [Nutrition Advice & Recipes - The National Pancreas Foundation](https://www.pancreasfoundation.org/nutrition-advice-recipes)

Thank you

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Genetic Causes of Pancreatic Diseases

Case-Based Discussions

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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



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Genetic Causes of Chronic Pancreatitis

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

PRSS1, serine protease 1; SPINK1, serine peptidase inhibitor Kazal type 1; CFTR, cystic fibrosis conductance regulator; CaSR, calcium-sensing receptor; CTRC, chymotrypsin C



MICHIGAN MEDICINE
UNIVERSITY OF MICHIGAN

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

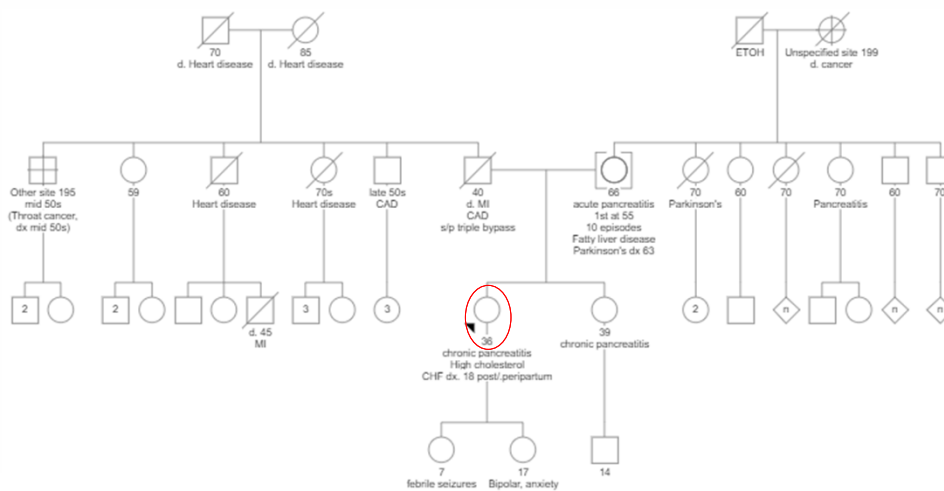
Case #1 Continued

- 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 Pedigree



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

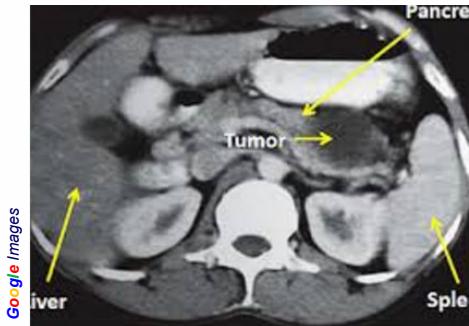
* *SPINK1*, serine peptidase inhibitor Kazal type 1



Pancreatic Cancer



Pancreatic Cancer Risk Factors



3 cm hypoattenuating mass in the tail of the pancreas

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

Yadav and Lowenfels. The epidemiology of pancreatitis and pancreatic cancer. *Gastroenterology*, 2013;144(6):1252-61



Differential Potential Genetic Causes of Pancreatic Cancer

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

BRCA, breast cancer gene; PALB2, partner and localizer of BRCA2; ATM, ataxia-telangiectasia; CDKN2A, cyclin-dependent kinase inhibitor 2A; STK11, serine/threonine kinase 11; MLH1, mutL homolog 1; MSH, melanocyte stimulating hormone; PMS, photoperiod-sensitive genic male sterility; PRSS1, serine protease 1; SPINK1, serine peptidase inhibitor Kazal type 1;



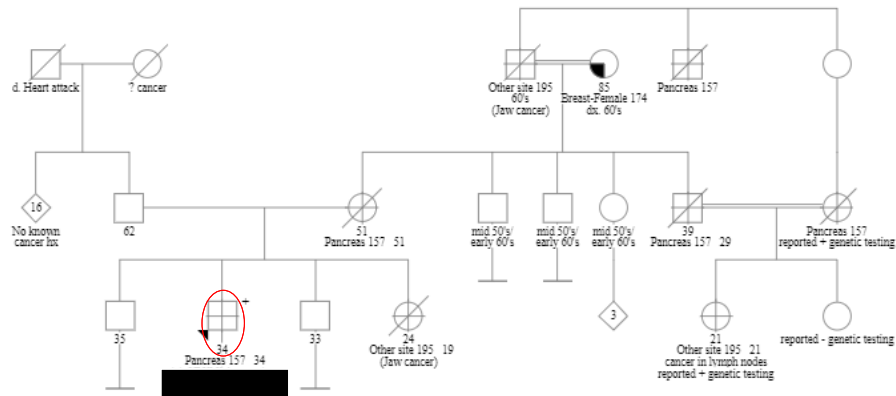
Case #2

- 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 Pedigree-3 Generation



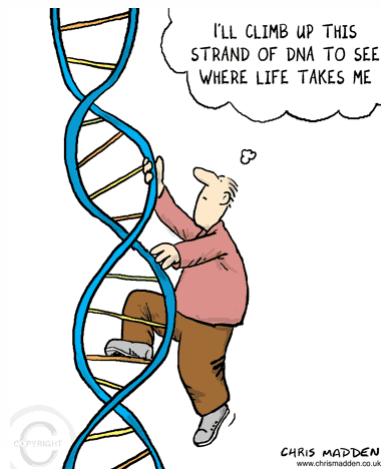
Case #2: Genetic Testing Results

CDKN2A* pathogenic variant: Familial Melanoma

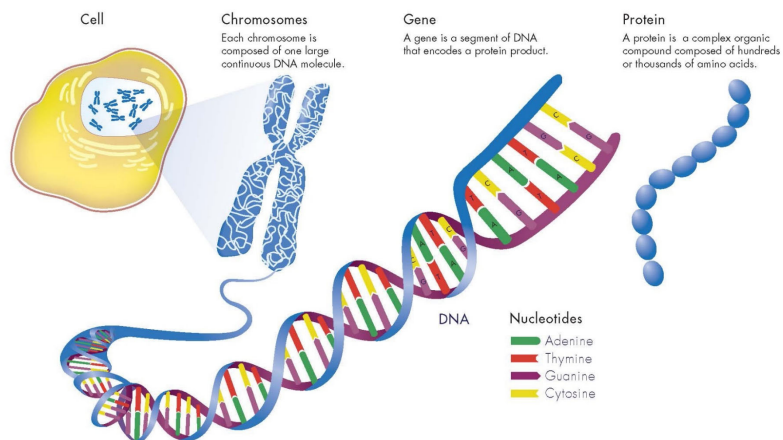
- Associated with a >15% lifetime risk of pancreatic cancer
- Risk of melanoma 28-76%, recommend annual dermatology visit
- Annual pancreatic cancer screening
- Recommend testing for family members

Genetics 101

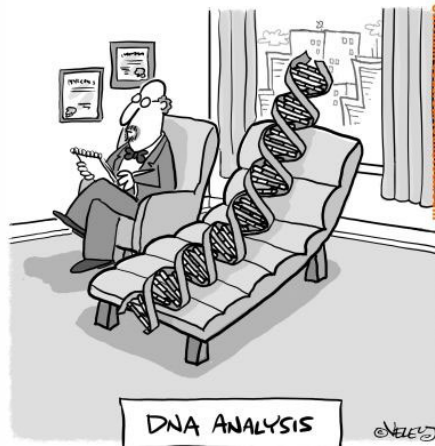
Back to high school biology class



Chromosome to Gene to Protein



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?

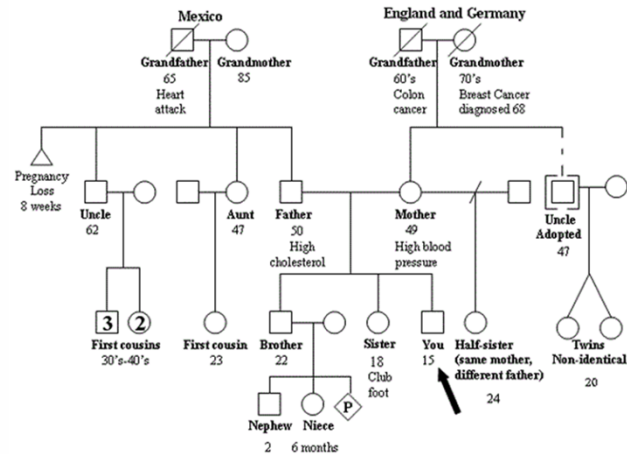
- Visits typically last 30-75 min, depending on the reason for referral
- Your genetic counselor will:
 - Explore your family health history
 - Discuss the reason for the referral
 - Talk about decisions that may need to be made
 - Help you understand what tests are available, what those tests may show, 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

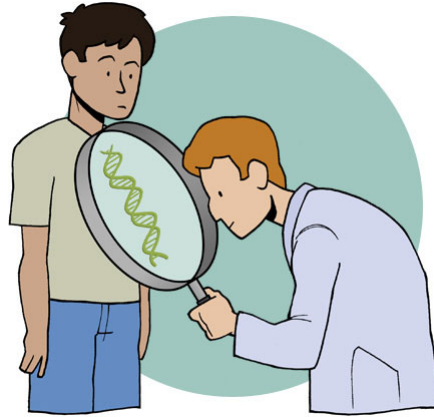
- Medical and health information about a person & blood relatives
- Give clues to conditions that may run in a family
- Helps identify individuals who are at an increased risk of developing those conditions



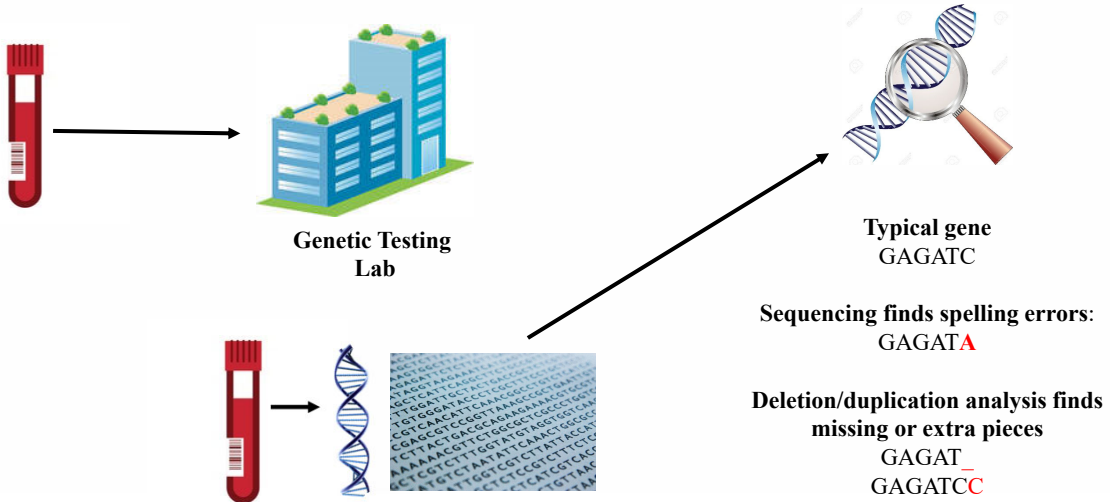
Important information to collect

- 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?



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 preform 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?

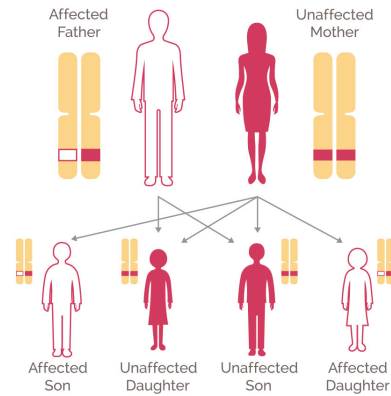
- Health Management/Surveillance
 - Specific guidelines or screening recommendations for your medical management
 - Find a healthcare provider who is familiar with your condition and make them your point person
 - High Risk Cancer Clinics
 - Specialist (e.g. Gastroenterologist, OB/Gyn, Geneticist, etc.)
 - 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!

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
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Panel Discussion

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
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Elena Stoffel, MD, MPH

Panel Discussion



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

Precision Medicine

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



--National Institutes of Health

*What Treatment is best for **ME?***

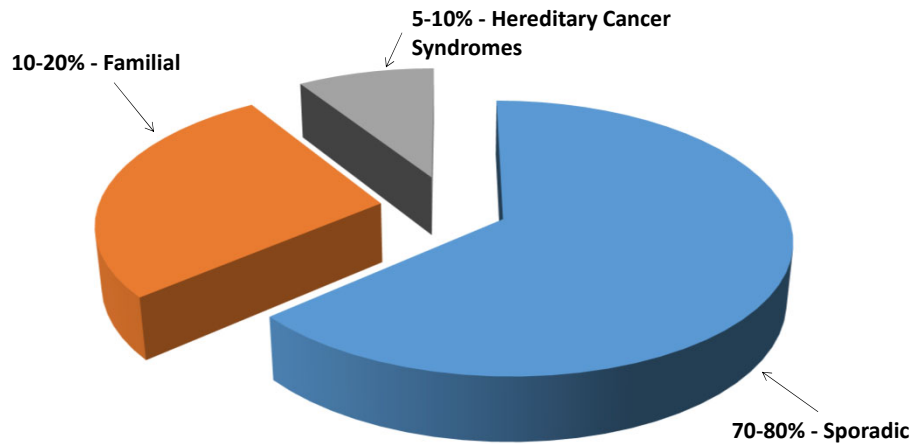
Objectives

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

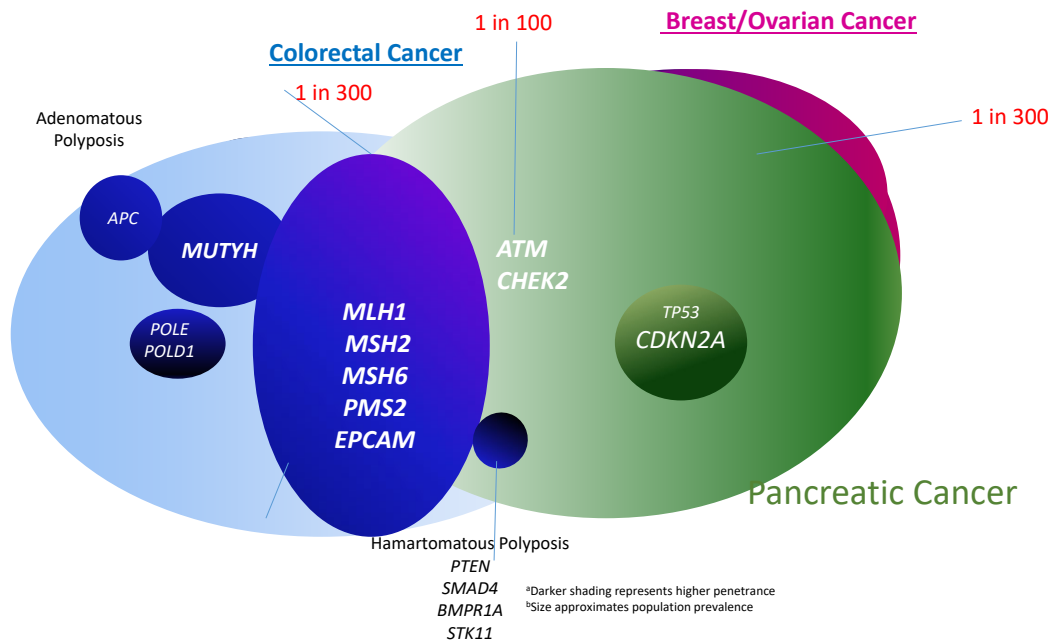
Case Example

- “My sister was just diagnosed with pancreatic cancer.
 - *What (if anything) do we need to do?*

Genetics and Cancer Risk



Genetic Predisposition to Cancer



Families with Genetic Risk are Underdiagnosed

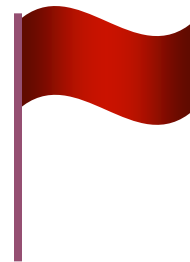
- 1 in 300 people carry gene changes associated with Hereditary Breast Ovarian Cancer Syndrome (BRCA)
- 1 in 300 people carry gene changes associated with Lynch Syndrome
- 1 in 100 people carry changes in ATM gene
- 1 in 31 people carry changes in CFTR gene
- *How do we identify and intervene early?*



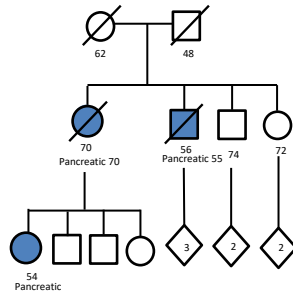
Image © Ralph A. Clevenger

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?”

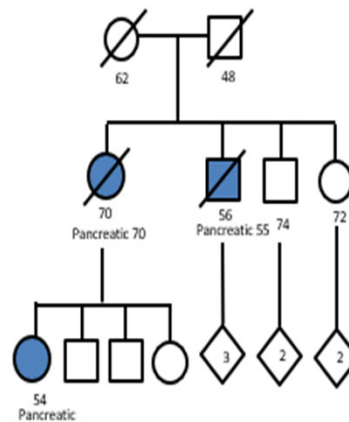


Genetic testing in sister revealed a pathogenic variant in BRCA2—
This information changes management
AND
makes predictive testing available to other family members!

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

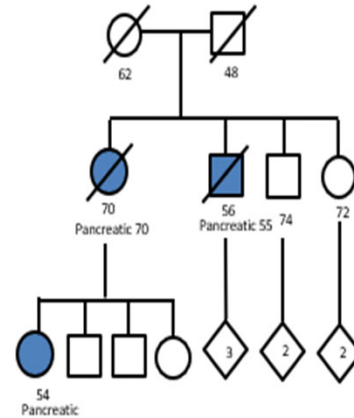


BRCA, breast cancer gene

PARP, Poly (ADP-ribose) polymerase

Why is a genetic diagnosis important?

- Use of specific cancer therapies that target the cause of the cancer
 - PARP inhibitor therapy for BRCA mutated tumors can improve survival
- Screening for other related cancer types
 - Specialized breast cancer screening for carriers of *BRCA1* or *BRCA2*
 - Screening for pancreatic cancer



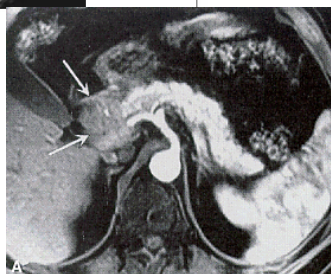
BRCA, breast cancer gene

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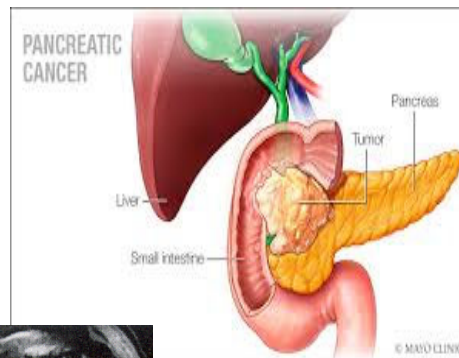
Screening for Pancreatic Cancer



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

The New York Times Magazine
My Genomic Self

Countdown on Iraq • The Obama Effect
U.S. News
A WORLD REPORT
Reading Your Genes
NEW DO-IT-YOURSELF TESTS CAN SHOW YOUR RISK OF SERIOUS DISEASE. BUT HOW GOOD ARE THEY?

Invention of the Year
1. The Retail DNA Test
By ANITA HAMILTON Wednesday, Oct. 29, 2008

YOUR LIFE: decoded
A new \$1,000 DNA test can tell you how you'll live—and die. Welcome to the Age of the Genome.

Slide courtesy of S. Roberts PhD

I Had My DNA Picture Taken, With Varying Results



*Not all genetic tests
are
CLINICAL GENETIC
TESTS!*

Ozler Muhammad/The New York Times
Kira Peikoff, 28, had her DNA tested by three direct-to-consumer companies, and the results didn't agree.

By KIRA PEIKOFF
Published: December 30, 2013 | 421 Comments

Who should undergo clinical genetic testing for pancreatic disease?

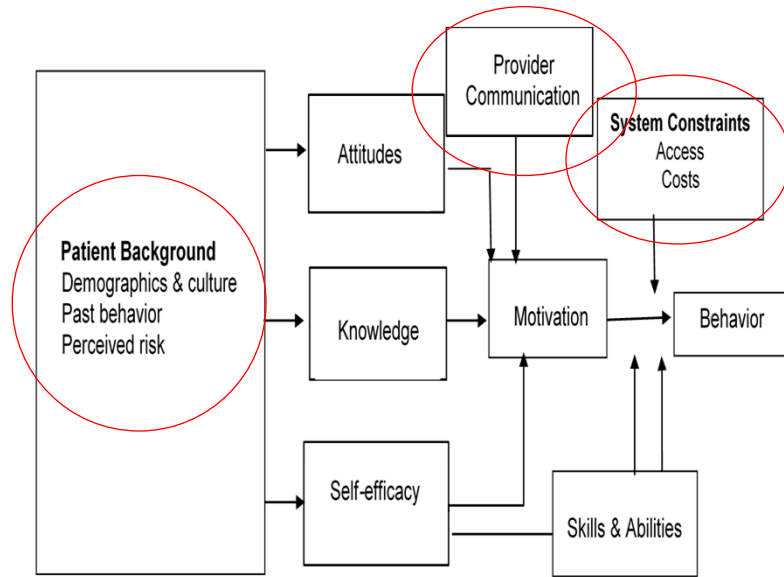
Pancreatic Cancer

- 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, CTSC, CASR, CFTR*

**What
Influences
whether
a patient gets
genetic testing?**



Adaptation of the Integrative Model of Behavior

MDHHS
Michigan Department of Health & Human Services

Search

Assistance Programs | Adult & Children's Services | Safety & Injury Prevention | Keeping Michigan Healthy | Doing Business with MDHHS | Inside MDHHS

Adult & Children's services

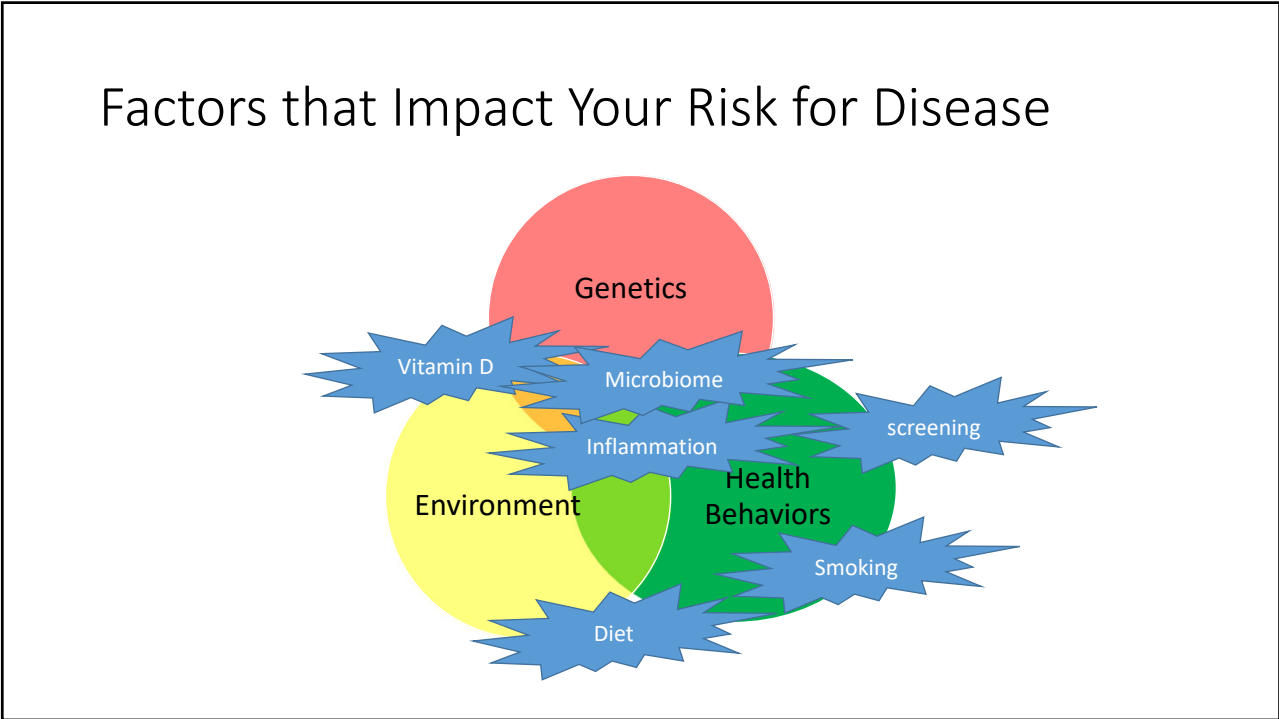
MDHHS / ADULT & CHILDREN'S SERVICES / CHILDREN & FAMILIES / HEREDITARY DISORDERS

MDHHS Cancer Genomics Program

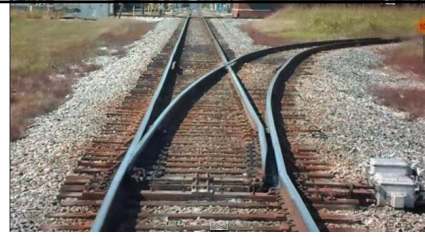
"My Dad told me he had colorectal cancer. I decided to stop asking questions and start getting answers."

Are you a healthcare provider? Visit our **HEREDITARY CANCER TOOLKIT** for free clinical and educational resources.

Find a genetic specialist near you:
Michigan Department of Health and Human Services Cancer Genomics Michigan.gov/mdhhs



Summary



- Talk to your medical team about your family health history
 - Does this meet criteria for genetic testing?
- Genetics \neq 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



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Panel Discussion

**CLOSING
 REMARKS**

Panel Discussion



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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** —————>





PANC WALK

NOVEMBER 13TH
2021

PAINT CREEK TRAIL

11:30 AM - 2:30 PM

FAMILY AND PET FRIENDLY!

DONATE HERE:



Check us out online:
Pancreasfoundation.org

Find us on [facebook.com/michiganpancreasfoundation.org](https://www.facebook.com/michiganpancreasfoundation.org)

REGISTER

<https://give.pancreasfoundation.org/ge/pancwalk>



NOV 13 2021 PANC WALK

1ST 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

