Mission:Cure

July 29th, 2025

Autoimmune Pancreatitis (AIP): Understanding Types, Diagnosis & Treatment Options

Dr. Yasmin Hernandez-Barco

Katharine Provencher, MSW

About Mission: Cure

Mission: Cure is a nonprofit founded in 2017 for & by patients to find treatments & improve the lives of people suffering from pancreatitis.

Awarded grant from Chan-Zuckerberg Initiative Science for high-potential patient-led rare disease organizations

Actively working with 6 pharma/biotech companies & 8 academic medical centers on drug development for chronic pancreatitis

Bringing new funding from impact investors to therapeutic development projects

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Megan & Eric

Linda & Amy

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Agenda

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Pancreatitis Natural History	Dr. Yasmin Hernandez-Barco
AIP Types, Diagnosis Considerations	Dr. Yasmin Hernandez-Barco
Treatments, Ongoing Management	Dr. Yasmin Hernandez-Barco
Patient Advocacy, IgG4-RD	Katharine Provencher
Q & A Session	Linda Martin
Closing	Olivia Zeiden

OBJECTIVES

Autoimmune Pancreatitis (AIP)

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1. Understand AIP, its subtypes (Types 1, 2, & 3) & why accurate classification matters
2. Connection to IgG4-Related Disease (IgG4-RD)
3. Diagnostic criteria & challenges
4. Latest treatment options to support informed care decisions
5. Monitoring & treating complications

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Understanding Autoimmune Pancreatitis (AIP)

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Autoimmune Pancreatitis (AIP)

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A rare & chronic form of recurrent acute & chronic pancreatitis (CP)
Body's immune system mistakenly attacks the pancreas: ~ 2-5% of all CP cases from AIP

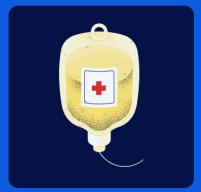
Types of AIP

Type 1 AIP

- IgG4-Related Disorder
- IgG4-Sclerosing Cholangitis (IgG4-SC/ ISC) or IgG4- related cholangitis (IRC)
- Lymphoplasmacytic sclerosing pancreatitis

Type 2 AIP

- Idiopathic Duct Centric Chronic Pancreatitis (IDCP)



Type 3 AIP

- Immune-checkpoint inhibitor pancreatic injury or pancreatitis (ICI- Pancreatic Injury)

Anatomy of Pancreas & Bile Ducts

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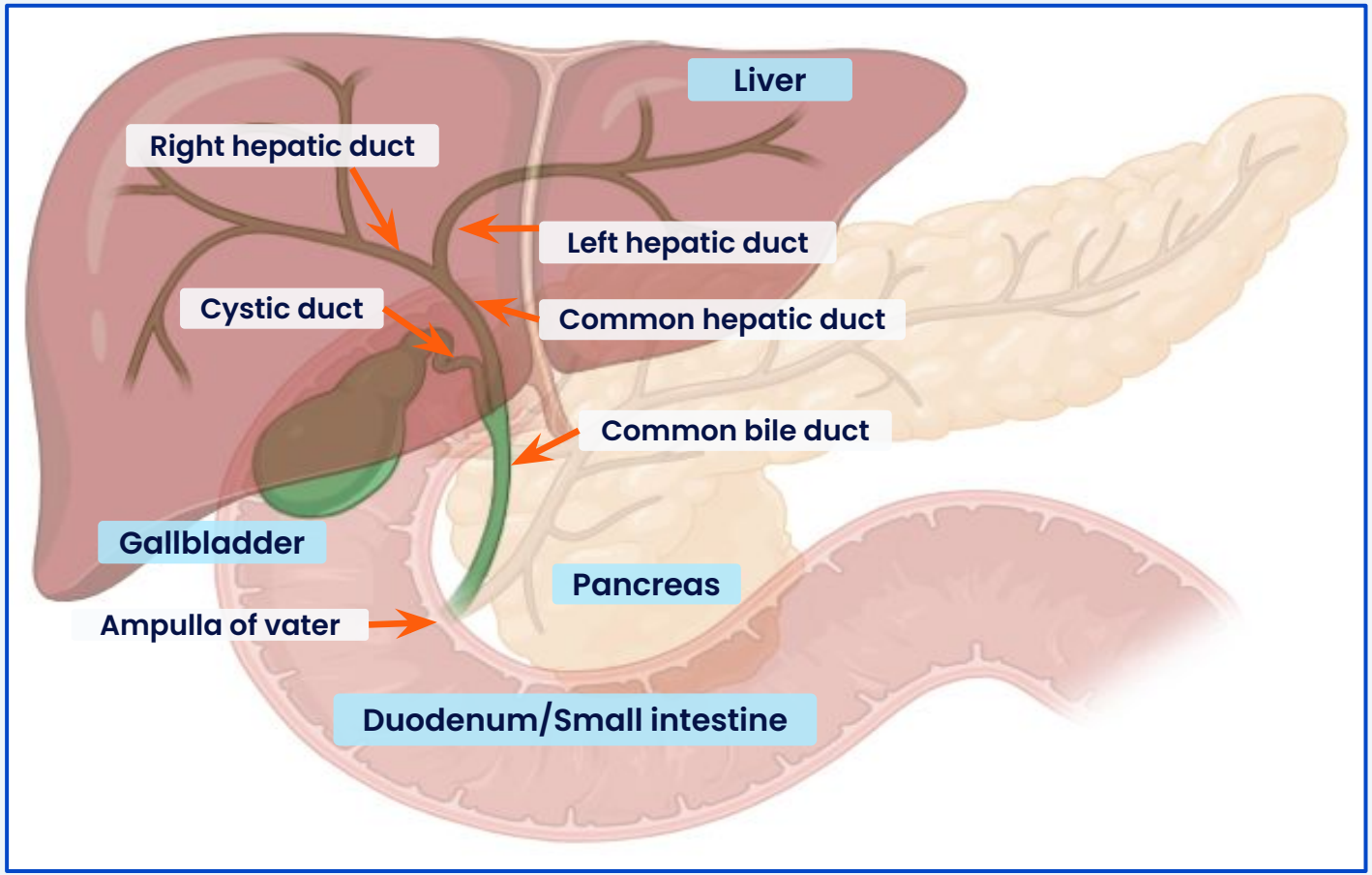

Natural History of Pancreatitis

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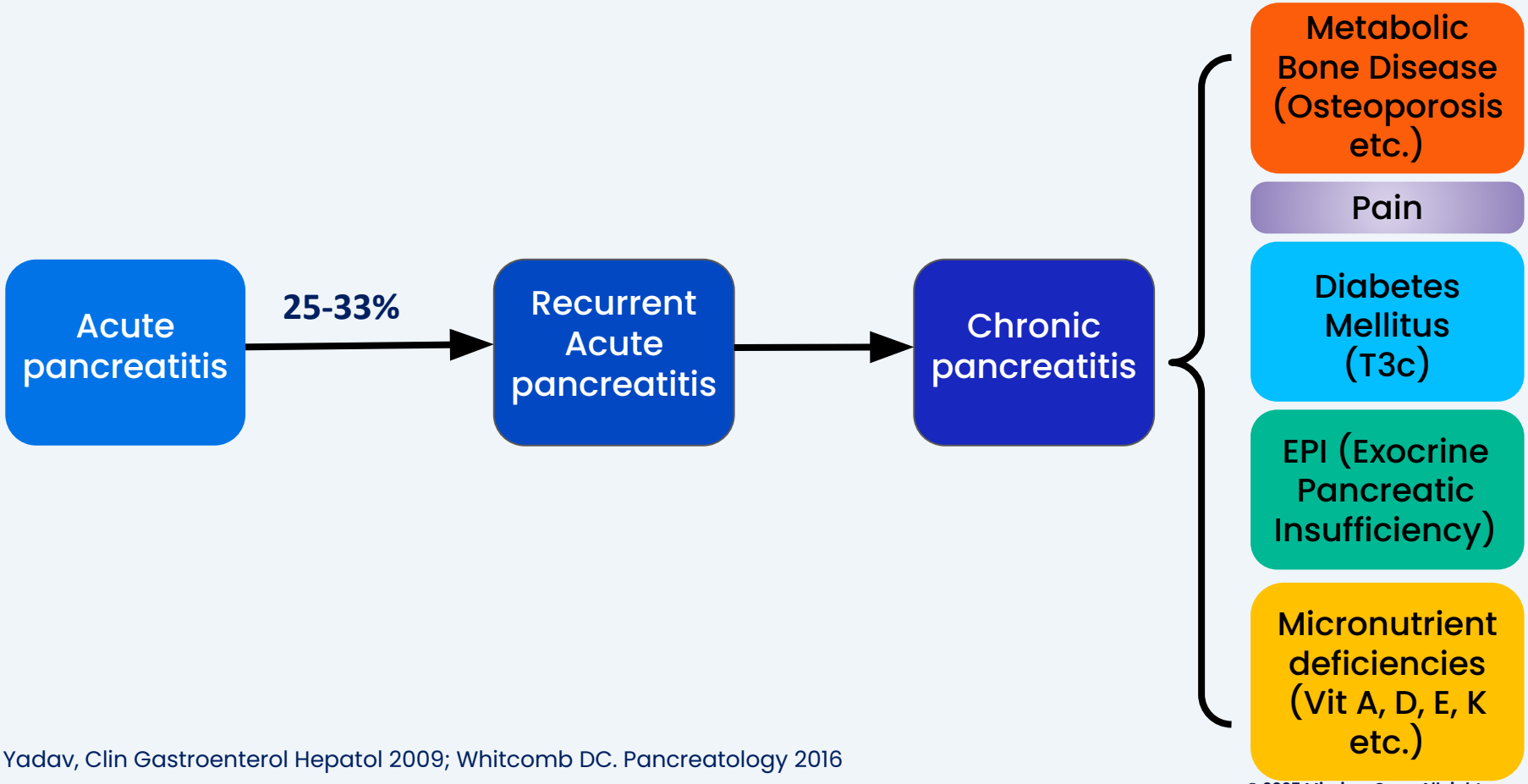

Yadav, Clin Gastroenterol Hepatol 2009; Whitcomb DC. Pancreatology 2016

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Why Cause Matters

TIGAR-O- Risk Factor Classification

TOXIC-METABOLIC

Drug induced, High trigs/calcium, DKA, CKD, Rare metabolic disorders, etc.

Avoid Toxins- No smoking/alcohol, Control Triglycerides/ Calcium/Others

IDIOPATHIC

Risk Modification*, Surveillance, Genetic Counseling

GENETIC

CFTR-Modulators; Risk Modification*, Genetic Counseling, Surveillance

AUTOIMMUNE

Steroids
Biologics
Immunosuppressants

RECURRENT & SEVERE ACUTE

Risk Modification*, Surveillance

OBSTRUCTIVE

Remove obstructions- Cholecystectomy (gallbladder removal) ERCP, Surgical

TREATMENT AND APPROACH MAY BE DIFFERENT

*Risk Modification: Diet low in processed & red meat & high in antioxidants

Adapted from Pham and Forsmark, 2018, Review Chronic Pancreatitis

Type 1 AIP or IgG4-RD AIP

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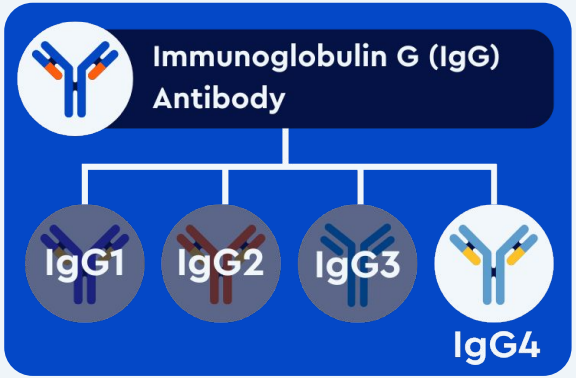
IgG Antibody

IgG4: Subset of IgG antibody



*IgG4-RD: Immunoglobulin G4 Related Disease
*Cholangitis: Bile ducts inflammation

IgG4-RD*: A Chronic Fibroinflammatory Disease (Inflammation → Organ Scarring)

- → Impacts pancreas: Type 1 AIP or IgG4-related pancreatitis
- → Impacts bile ducts: IgG4-related sclerosing cholangitis*
- → Can affect many other organs

In IgG4-RD:

- → Overactive Immune system
- → Too many IgG4 positive immune cells
- → Excess IgG4 in healthy organs = Chronic inflammation
- → Scarring or fibrosis = Affects organ function


Pancreas


Lungs


Salivary Glands


Kidneys

Type 1 AIP: Patient Profile

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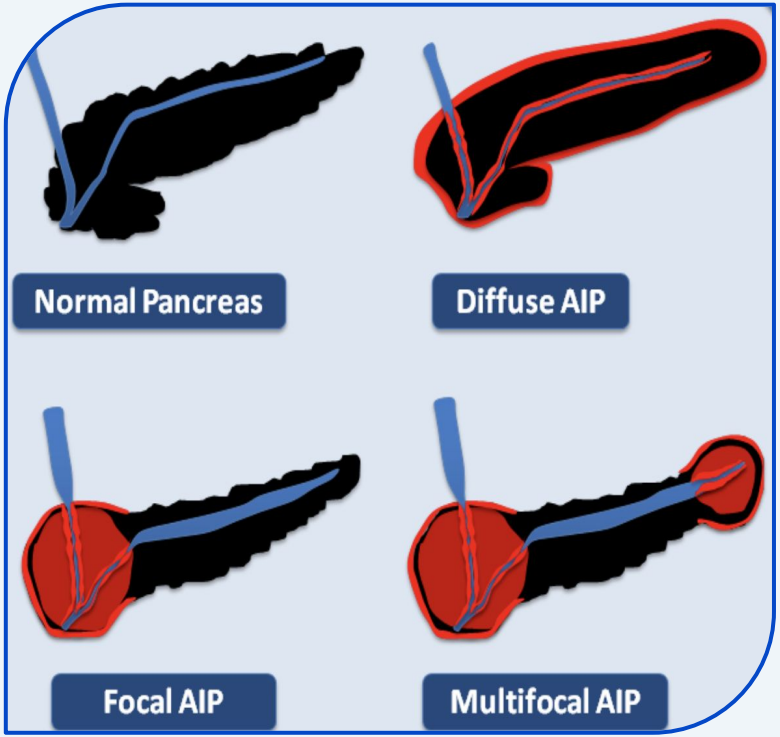
	Type 1 AIP Patient Data	Compared to Type 2 AIP
Age (years)	61.8 ± 15.3	*Older
Gender (Male %)	70%	*More Men vs Women
Imaging findings		
Diffuse swelling	30 (40%)	*Less common
Other features	48 (60%)	*Less common
Elevated IgG4 level (>140 mg/dL)	59 (80%)	*More common
Other organ Involvement	47 (60%)	*Only in Type 1
IBD* Association (Inflammatory Bowel Disease)	6%	*No significant difference
Relapse rate	47%	*Significantly higher



Adapted from Figure 4, RadioGraphics 2011; 31:1379–1402

Chari ST et al, Gastro 2010, 139: 140-8

Making The Right Diagnosis: Type 1 AIP

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Diagnosis Criteria: HISORt & American College of Rheumatology criteria for IgG4-RD

1. **H**istology/Immunostaining *(microscope study of pancreas biopsy)*
2. **I**maging *(e.g., CT scan, MRI, MRCP)*
3. **S**erology *(blood work)*
4. **O**ther organ involvement *(upto 10-11 other organs)*
5. **R**esponse to steroid therapy *(using steroid for diagnosis)*

NOT ONE SINGLE TEST CAN DIAGNOSE IgG4-RD! Requires combination of assessments

Diagnosis: H*ISORt

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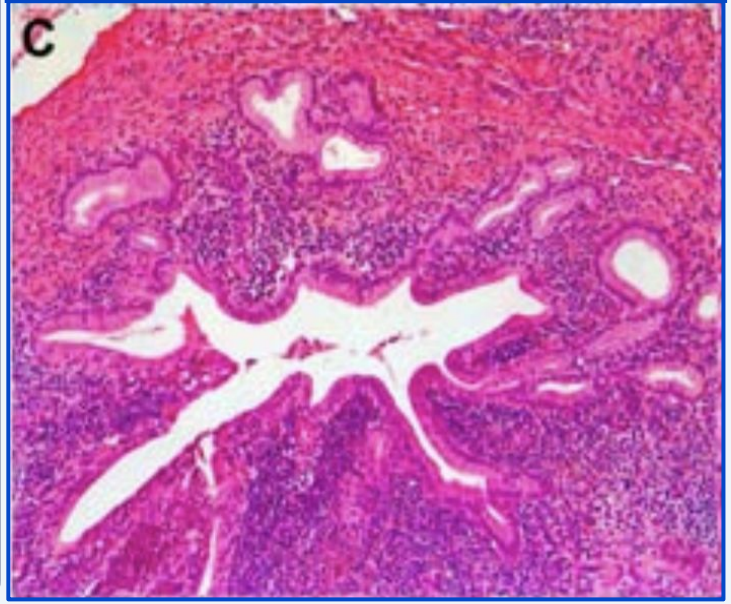
*H = Histology/Immunostaining

(Pancreas biopsy tissue, microscopic view)

***Periductal Lymphoplasmacytic Infiltration*:**

- ➔ Immune cells around ducts (lymphocytes + plasma cells)
- ➔ IgG4 +ve plasma cells seen on staining (supports diagnosis- doesn't confirm)
- ➔ Ducts show scarring & narrowing
- ➔ Normal biopsy doesn't rule out AIP

Type 1 AIP: Severe periductal lymphoplasmacytic infiltration



C Type 1 AIP: Severe periductal lympho-plasmacytic infiltration causing partial stenosis of a medium-sized pancreatic duct (haematoxylin and eosin, x100), Detlefsen S, Löhr JM, Drewes AM, Frøkjær JB, Klöppel G. doi: 10.2174/187221311795399228. PMID: 21453268.

Diagnosis: HI*SORt

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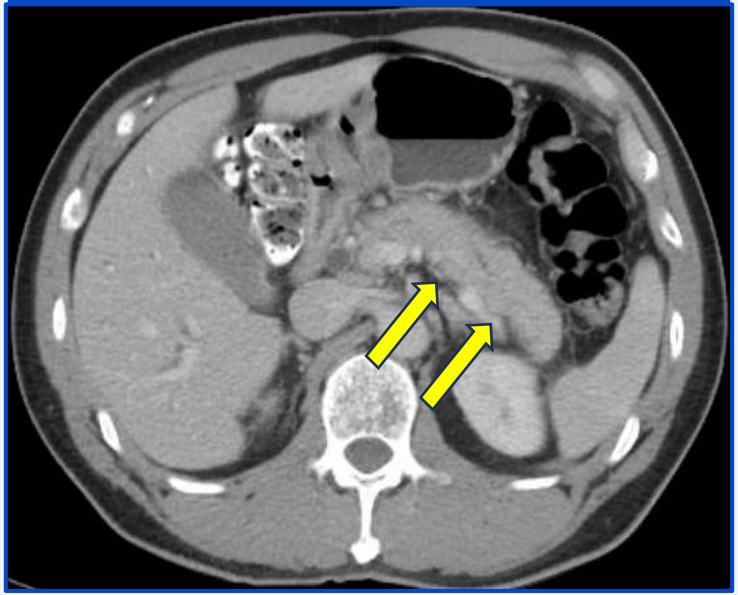
* I = Imaging (e.g., CT, MRI, MRCP)

- “Sausage shaped pancreas”- Diffuse pancreatic enlargement- loss of lobulations
- 1/3rd pancreatic duct stricture (narrowing) ***without*** downstream dilation (widening)
- Multifocal pancreatic duct strictures or beaded pancreatic duct
- “Halo-sign”
- Look for other organ involvement

Classic Imaging: Can diagnose AIP in 40% of cases



Diagnosis: HI*SORt

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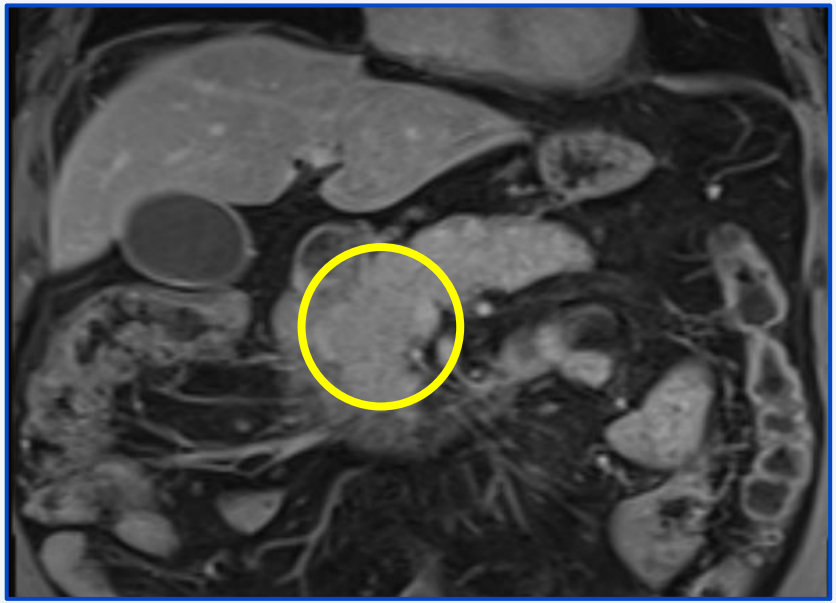
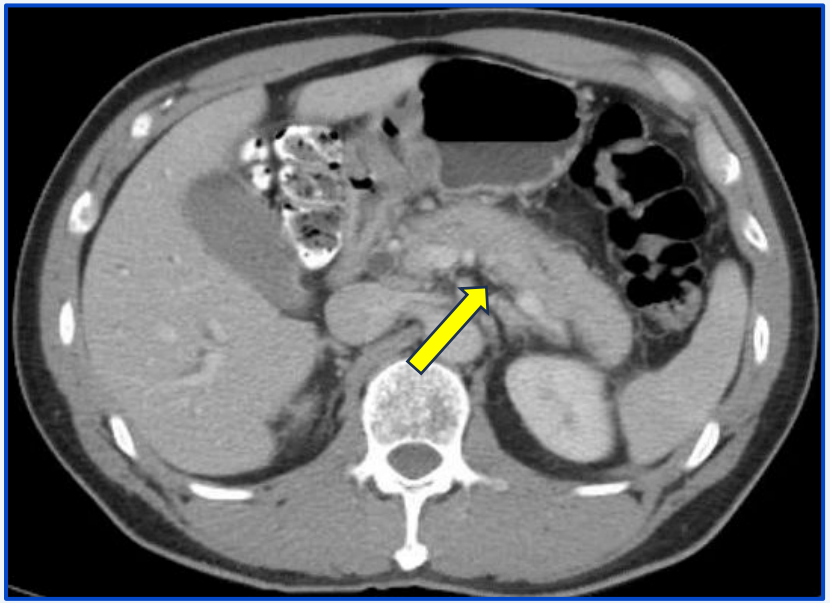
Mass-forming/Focal Imaging



- Requires a biopsy
- Steroids with short interval imaging

Diffuse Involvement Imaging



- Other causes of pancreatitis need to be ruled out

Diagnosis: HI*SORt

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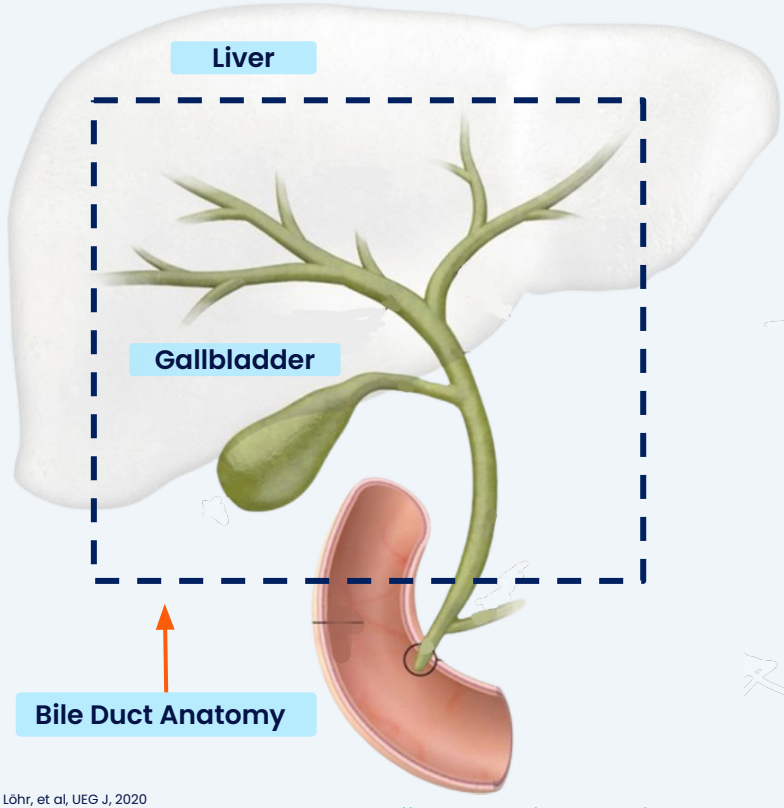
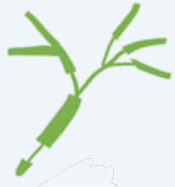
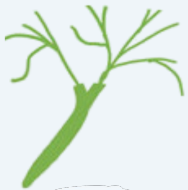
IgG4-sclerosing cholangitis (IgG4-SC/ ISC) Or IgG4- related cholangitis (IRC): Bile Duct Involvement
IgG4-SC in ~ 70% of Type 1 AIP (Isolated bile duct involvement-only 10%)



TYPE 1 IRC
Intrapancreatic segment only



TYPE 2A IRC
Diffuse intrahepatic & extrahepatic stenosis



TYPE 2B IRC
Diffuse intrahepatic & extrahepatic stenosis

TYPE 3 IRC
Hilar stenosis + Distal choledochal stenosis

TYPE 4 IRC
Isolated hilar stenosis

Löhr, et al, UEG J, 2020
Fig 1: Adapted from figure 5- Normal biliary anatomy- https://radiologykey.com/the-biliary-tree/
Fig 2: Adapted from IgG4-Related Sclerosing Cholangitis: Rarely Diagnosed, but not a Rare Disease - Scientific Figure on ResearchGate, https://www.researchgate.net/figure/Schematic-classification-of-IgG4-related-sclerosing-cholangitis-by-cholangiography_fig1_357234305

Diagnosis: HIS*ORt

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*S = Serology (Blood Work)

- IgG4 elevated in (75%)
- IgG (60%)
- IgE (60%)
- C3/C4 (25%)

A positive IgG4 does **NOT** confirm diagnosis/

- High IgG4 levels = Higher Relapse Risk *(95% CI: 1.2-32 p<0.01)*
- Liver Function Tests: Higher with bile duct involvement (monitor for treatment response)
- Exclusion Clues: Fever, no steroid response, low white blood cells/platelets, high eosinophils, ANCA+, anti-Ro/La, splenomegaly, or rapid imaging changes

Wallace et al, Rheumatology 2016

Diagnosis: HISO*Rt

***O = Other organ involvement**

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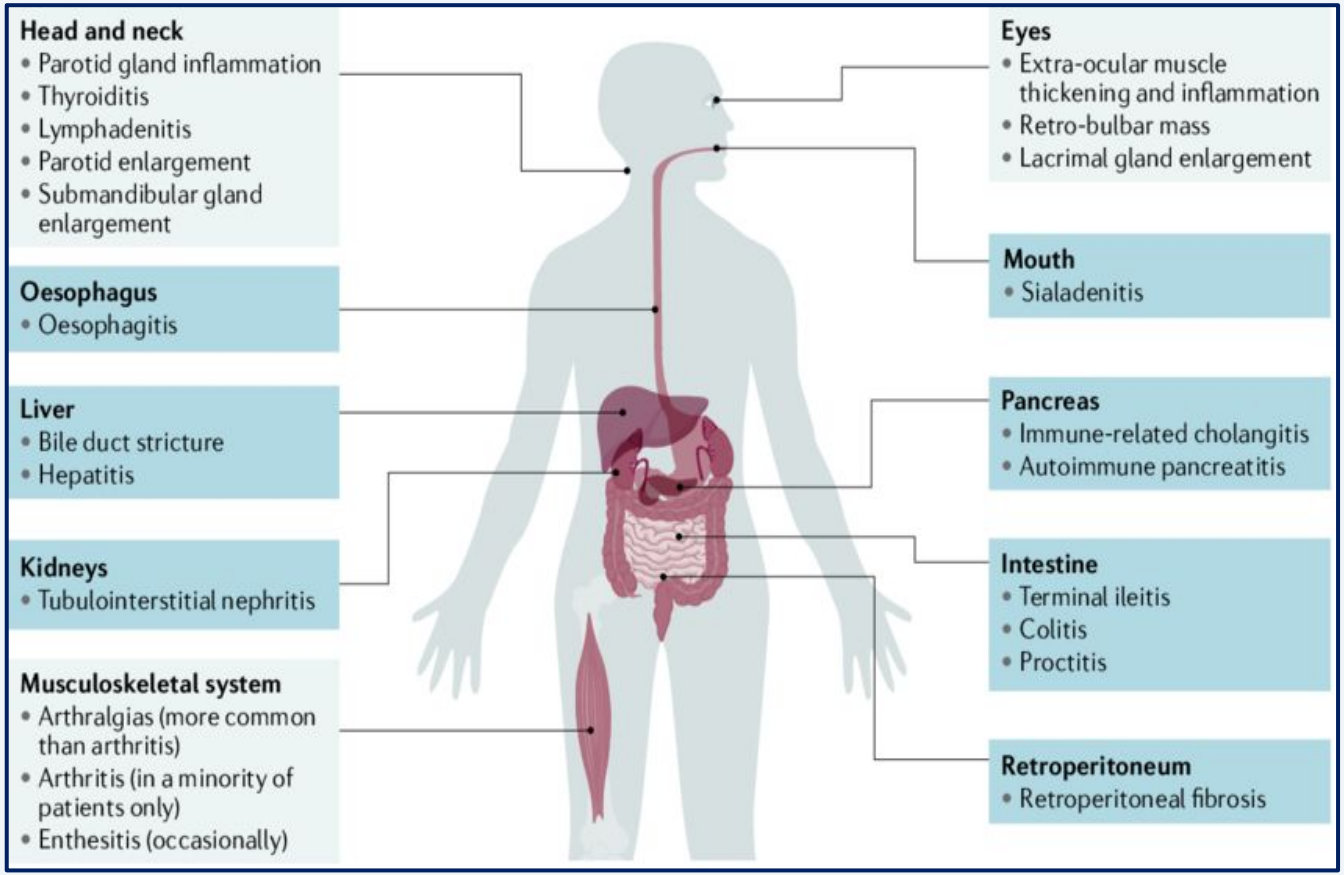

→ 10-11 organs primarily affected (multi-organ involvement)

→ 60% of patients may have **irreversible organ damage** at diagnosis

Löhr, Matthias & Vujasinovic, Miroslav & Rosendahl, Jonas & Stone, John & Beuers, Ulrich. (2021). IgG4-related diseases of the digestive tract. Nature Reviews Gastroenterology & Hepatology. 19. 1-13. 10.1038/s41575-021-00529-y. Fig. 1: IgG4-related disease in the gastrointestinal tract.

Diagnosis: HISO*Rt

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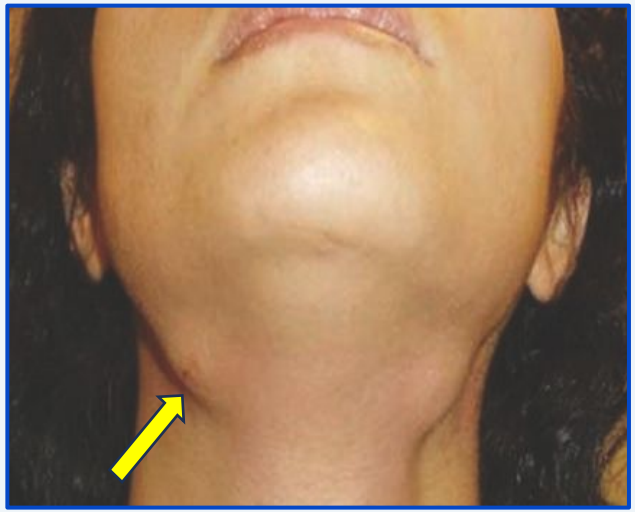
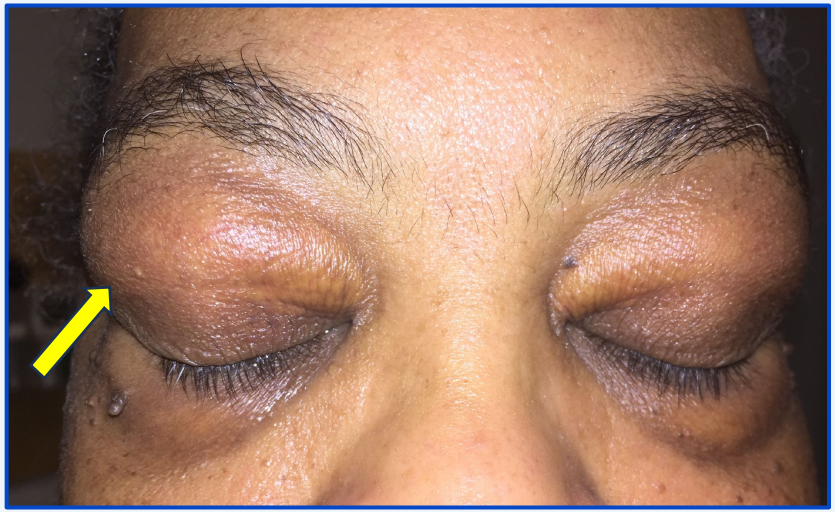
***O = Other organ involvement:** Extra-pancreatic organ involvement

Sialadenitis with salivary gland enlargement



Lacrimal gland/ Tear gland enlargement



Images courtesy of Dr. John Stone, Professor of Medicine, Harvard Medical School, The Edward A. Fox Chair in Medicine, Massachusetts General Hospital

Diagnosis: HISO*Rt

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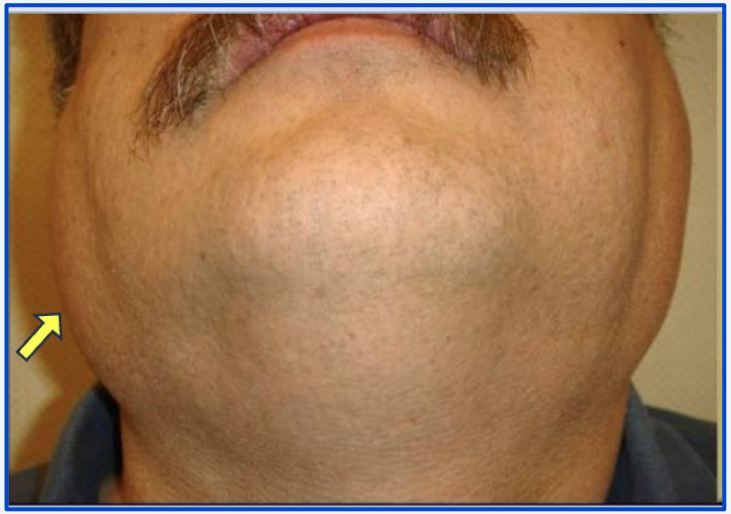
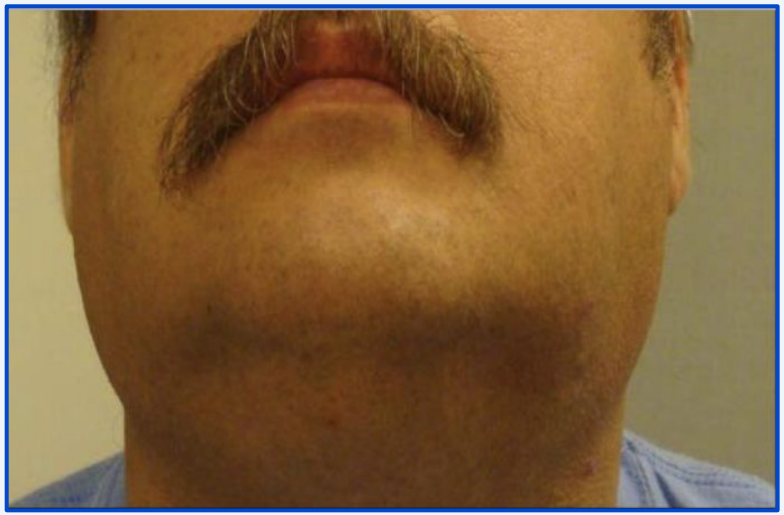
***O = Other organ involvement:** Extra-pancreatic organ involvement

Parotid gland enlargement



Normal parotid glands after treatment



Images courtesy of Dr. John Stone, Professor of Medicine, Harvard Medical School, The Edward A. Fox Chair in Medicine, Massachusetts General Hospital

Diagnosis: HISOR*t

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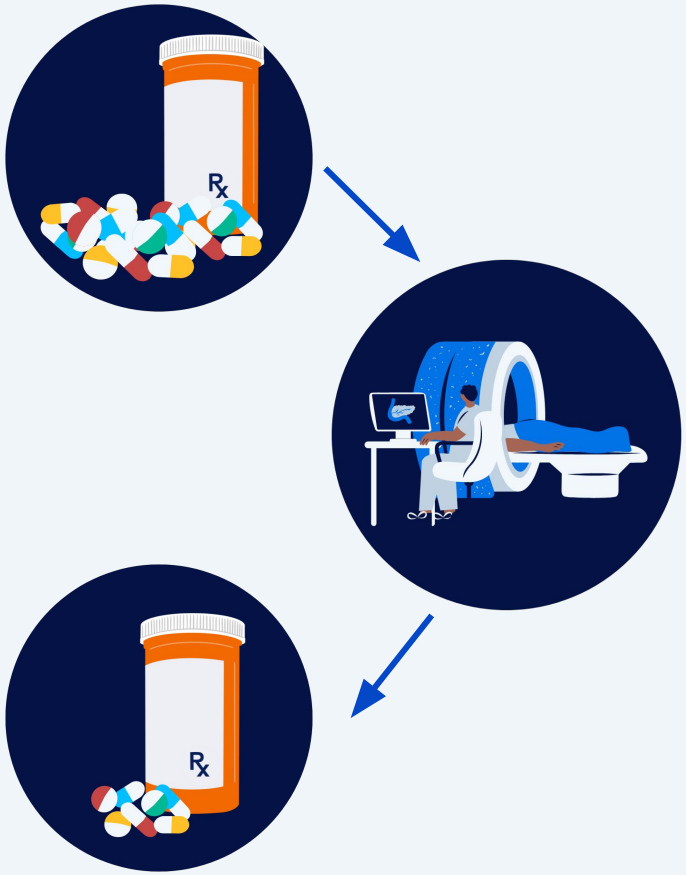
*R = Response to steroid therapy

***If steroids used for diagnosis*:**

- Prednisone 40 mg/orally/once daily for 4 weeks
- Short interval CT/MRI/MRCP in ~4 weeks to ensure resolution of imaging findings
- If responding, then taper by 5 mg per week for a total of 12 weeks



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Treatment Goals: Type 1 AIP/IgG4-SC

- Induce + Maintain REMISSION* (reduce disease-driving inflammation)
- Treat
  - Symptomatic patients with pancreatic or other organ involvement
  - Patients with risk for severe or irreversible organ failure
- Maintenance therapy to prevent relapse
  - Optimal choice & timing is individualized

*Remission: Absence of symptoms & inflammation + improvement on imaging & lab tests after treatment begins

Hart, Gastro 2015, Lohr et al UEG J 2020

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Treatment Approach: Type 1 AIP/IgG4-SC

STEROIDS

Suppress immune system activity to reduce inflammation & induce remission*

IMMUNOMODULATORS

Help maintain remission by balancing immune response & reducing need for prolonged steroid use

BIOLOGICS*/ B-CELL DEPLETION

Target & reduce B-cells (plays key role in Type 1 AIP) to control inflammation & prevent disease relapse

*Remission: Absence of symptoms & inflammation + improvement on imaging & lab tests after treatment begins.
*Biologics: Therapies made from living organisms or their products; target specific components of the immune system.

Treatment: Steroids

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E.g., Prednisone, Methylprednisolone & Prednisolone

- 99.6% effective at inducing remission, 40-50% relapse rate
- Risk Factors for relapse:
  - *Proximal cholangiopathy (upper bile duct disease)*
  - *Persistently high IgG4 despite therapy*
  - *Multi-organ involvement*
- Steroid Therapy Trial: Prednisone 20-40 mg/day for 4 weeks, taper by 5 mg/week (North America & Europe)
- Can use steroids for maintaining remission ~25% relapse rate on low-dose (Japan & Asia)

Chari ST et al, Gastro 2015; Hart, Gut 2013; Okazaki K et al, Pancreatology 2017

Treatment: Immunomodulators

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E.g., Azathioprine, 6-Mercaptopurine (6MP), Mycophenolate Mofetil (MMP), Methotrexate

- Inflammatory Bowel Disease (IBD)-level dosing needed for effectiveness
  - *Can't induce remission, but maintains in ~ 50-60% patients*
- For high-risk individuals or early relapse (<1 year)
- Not commonly used:
  - *Patient response hard to predict*
  - *Uncertain long-term remission*

Table 4 Details of immunomodulator (IM) treatment in patients* treated with azathioprine (AZA), 6-mercaptopurine (6-MP) or mycophenolate mofetil (MMF)

	AZA (n=31)†	6-MP (n=6)	MMF (n=11)
Duration from diagnosis to drug initiation (months)	10.0 (1.1–266)	9.5 (5.5–37.7)	11.0 (1.0–55.6)
Dose (mg)	150 (50–200)	100 (37.5–200)	1750/day (1000–2000)
Dose (mg/kg/day)	1.9 (0.5–2.5)	1.5 (0.7–2.6)	–
Duration of treatment (months)	9.8 (0.7–43.9)	9.0 (0.2–17.5)	17.4 (3.0–50.8)
Indication for drug discontinuation			
Disease remission	7/30 (23%)	3/6 (50%)	3/11 (27%)
Relapse on treatment	9/30 (30%)	1/6 (17%)	3/11 (27%)
Side effects	5/30 (17%)	2/6 (33%)	0/11 (0)
Continued at follow-up	9/30 (30%)	–	5/11 (45%)

Hart, Gut 2013;doi: 10.1136/gutjnl-2012-302886. Epub 2012 Aug 30. PMID: 22936672.

Treatment: Biologics/ B-Cell Depletion

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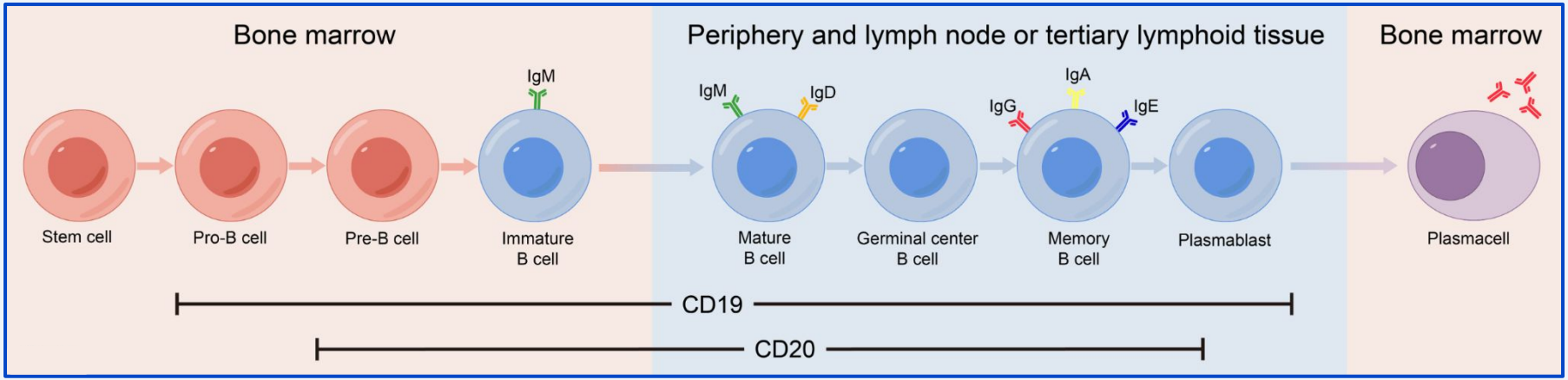
E.g., Rituximab, Rituximab biosimilars, Inebilizumab, Others under study



Adapted from Figure 1 Expression of cell surface antigens during B-cell differentiation., Shang, H., Shen, X., Yu, X., Zhang, J., Jia, Y., & Gao, F. (2024). B-cell targeted therapies in autoimmune encephalitis, Frontiers in Immunology, 15, 1368275. https://doi.org/10.3389/fimmu.2024.1368275

- B cells: White blood cells- Produce antibodies (including IgG4)- Develop in bone marrow
- In Type 1 AIP: Overactive B cells = Excess IgG4 + Drive inflammation
- CD19 & CD20: B cell surface markers involved in immune signaling & activation
- CD19: Found on most B cells throughout development
- CD20: Found only on mature B cells
- CD19 & CD20 Targeted Therapies: Reduce B cell activity + Lower IgG4 levels

Treatment: B-Cell Depletion

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IgG4-RD Pathophysiology*

B cells = 'Alarm system'

CD4+ cytotoxic T cells = 'Responders'

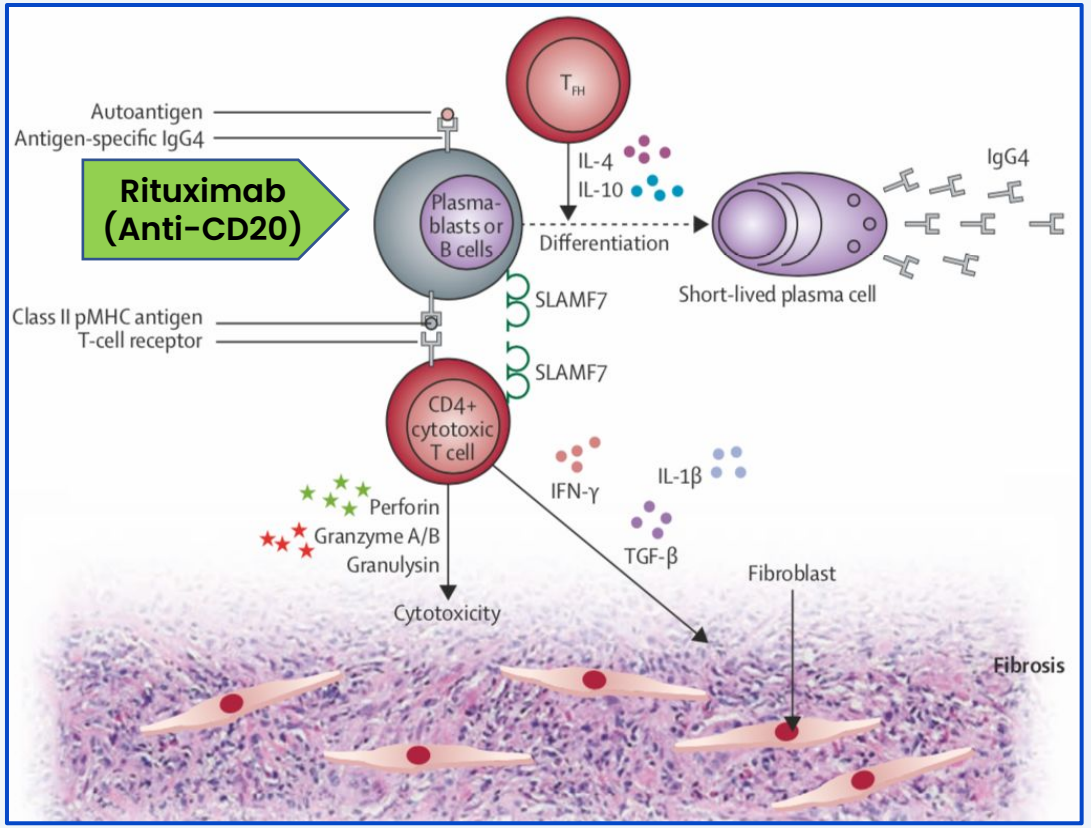
'Alarm' alerts 'Responders', they:
- ➔ May overreact
- ➔ Cause inflammation & damage

CD20 = On/Off switch on mature 'alarms'

Anti-CD20 therapy = Turns off mature 'alarms'

Fewer 'alarms':
- ➔ Responders calm down
- ➔ Organs stay safe from unnecessary attack

*Pathophysiology: How disease works



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Treatment: B-Cell Depletion

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IgG4-RD Pathophysiology*

B cells = 'Alarm system'

CD4+ cytotoxic T cells = 'Responders'

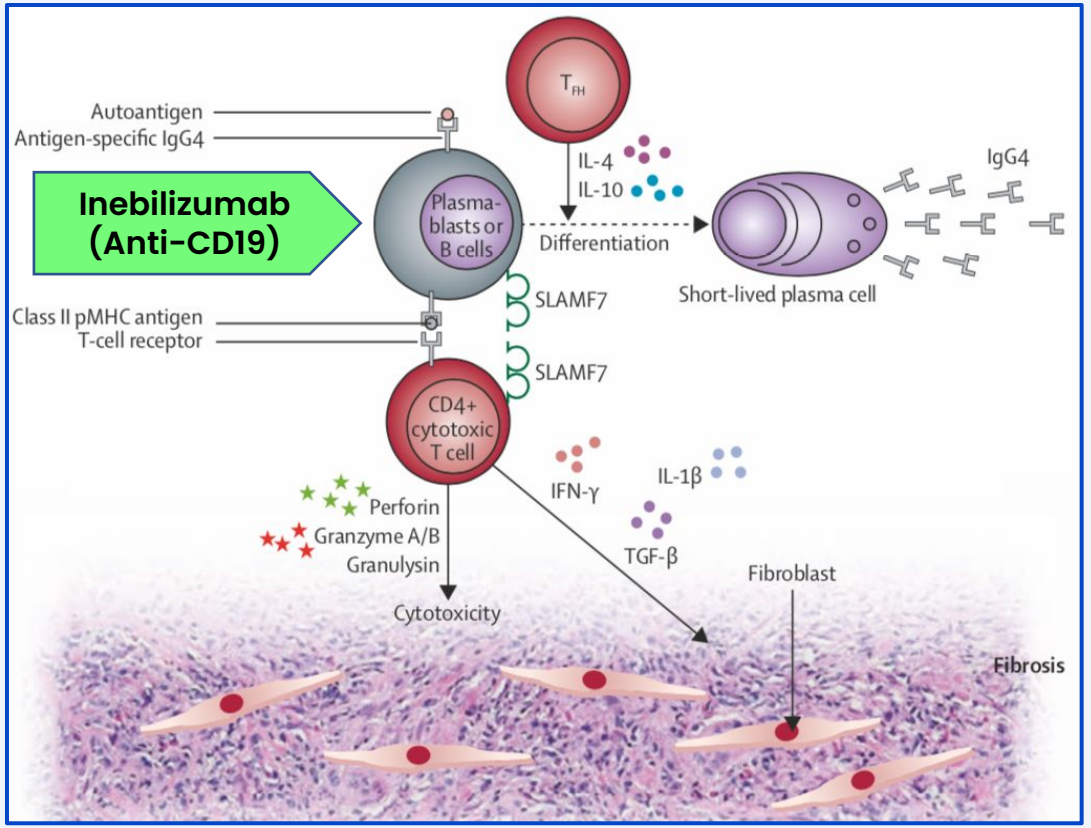
'Alarm' alerts 'Responders', they:
- ➔ May overreact
- ➔ Cause inflammation & damage

CD19 = 'GPS tag on alarm'- Can be found & turned off earlier

Anti-CD19 = Turns off more 'alarms', including early or hidden ones

Fewer 'alarms':
- ➔ Responders calm down
- ➔ Organs stay safe from unnecessary attack

*Pathophysiology: How disease works



Courtesy of Dr. John Stone, Professor of Medicine, Harvard Medical School, The Edward A. Fox Chair in Medicine, Massachusetts General Hospital

Treatment: Biologics/ B-Cell Depletion

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RITUXIMAB (ANTI-CD20)

- 2 infusions, 2 weeks apart, every 6 months (single agent)
- Induces & maintains remission, low relapse rate
- Maybe appropriate as 1st line agent if known serious steroid intolerance
- Multi-organ involvement

INEBILIZUMAB (ANTI-CD19)

- 2 infusions, 2 weeks apart, every 6 months (single agent)
- Broader targeting than CD20 therapies
- Induces & maintains remission, low relapse rate (need long term data). Reduces risk of flares by 87% vs placebo
- 1st FDA-approved therapy for IgG4-RD; suitable for multi-organ involvement, relapsing disease, steroid intolerance

Hart, Gut 2013, Majumder et al, CGH 2018; Carruthers, Ann Rheum Dis, 2015; Inebilizumab for Treatment of IgG4-Related Disease. N Engl J Med. 2025 Mar 27;392(12):1168-1177. doi: 10.1056/NEJMoa2409712. Epub 2024 Nov 14. PMID: 39541094.

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Treatment Approach Summary

CATEGORY/ DRUGS	PROS	CONS	TREATMENT: WHEN/WHY
STEROIDS/ GLUCOCORTICOIDS: **Prednisone**	• Very effective in inducing remission	• High relapse rate • Not for patients with contraindications* to steroids • Would avoid 2nd treatment trial in case of relapse	• Pancreas isolated disease • No evidence of pancreatic organ damage • Patients without steroid therapy contraindications*
IMMUNOMODULATORS: **Azathioprine, 6-MP, MMP + Low dose steroid maintenance**	• Lower relapse rate than prednisone alone	• Can't induce remission	• Can consider for 1st relapse
BIOLOGICS OR B CELL DEPLETION: **Rituximab/Rituximab biosimilars**	• Very effective in inducing remission • Low relapse rate	• Infusion reactions • Infectious complications	• **Multiorgan disease** • **Biliary involvement** • **IgG4 levels >280** • **Relapsed disease**
BIOLOGICS OR B CELL DEPLETION: **Inebilizumab**	• Very effective in inducing remission • Low relapse rate • 1st FDA-approved therapy for IgG4RD	• Infectious complications	• **Multiorgan disease**

*Contraindications: Conditions where steroids may be unsafe e.g., uncontrolled infections, severe diabetes, etc.

Summary: Type 1 AIP

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- Type 1 AIP & IgG4-SC: Part of IgG4-RD
- Treatment goal: TOTAL REMISSION (prevent organ damage)
- High relapse rates with steroid-alone treatment
- Biologics therapy for high-risk patients
  - Likely 1st line agent for most cases + multiorgan disease
- Choosing Rituximab & Inebilizumab:
  - Standard of care = Induce remission + Maintenance
  - Maintenance timing unclear & likely patient-specific
- Bile duct stenting may be avoided with early treatment
- Monitor:
  - Diabetes+EPI+Micronutrient deficiencies (once/yr)
  - Metabolic bone disease (once/2 yrs)

- Pancreatic Cancer (PDAC*) more common than Type 1 AIP & should be ruled out with biopsy

*PDAC: Pancreatic ductal adenocarcinoma

Type 2 AIP or IDCP: Diagnosis & Treatment

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Idiopathic Duct Centric Pancreatitis

- Pancreas-only, Cause- unknown; T-cells driven (versus B-cell driven Type 1 AIP)
- Can be diagnosed with pancreatic biopsy (gold standard)
- ~35% have Inflammatory Bowel Disease (IBD), especially Ulcerative Colitis
- Highly steroid responsive (Prednisone)
- Low relapse rate- Immunomodulators rarely needed. Biologics not effective
- Potential long-term endocrine & exocrine dysfunction (Diabetes & EPI)

	Type 2 AIP Patient Data	Compared to Type 1 AIP
Age (years)	47.7 ± 18.8	*Younger
Gender (Male %)	53.5%	*No gender bias
Imaging findings		
Diffuse swelling	3 (16%)	*Less common
Other features	16 (84%)	*More common
Elevated IgG4 level (>140 mg/dL)	8 (17%)	*Less common
Other organ Involvement	0	*Absent
IBD Association	16%	*Not statistically different
Relapse rate	<10%	*Significantly lower

Gut 1997; Am J Surg Pathol 2003; Gastroenterology 2010
Chari ST et al, Gastro 2010, 139: 140-8

Type 3 AIP: ICI Induced Pancreatic Injury

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Immune-Checkpoint Inhibitor (ICI) induced pancreatic injury (including pancreatitis)

- ICIs revolutionized cancer care
- Type 3 AIP triggered by ICIs used in cancer therapy
- ICI-pancreatitis: Immune-mediated phenomenon
- ICIs (anti-PD-1, PD-L1, CTLA-4) boost immune reaction- Increases T-cell activity to target tumors
- Can cause off-target immune attacks in other organs (including pancreas)
- 30–40% of ICI-treated patients develop immune-related side effects leading to ‘autoimmune-like’ phenomenon (irAEs*)

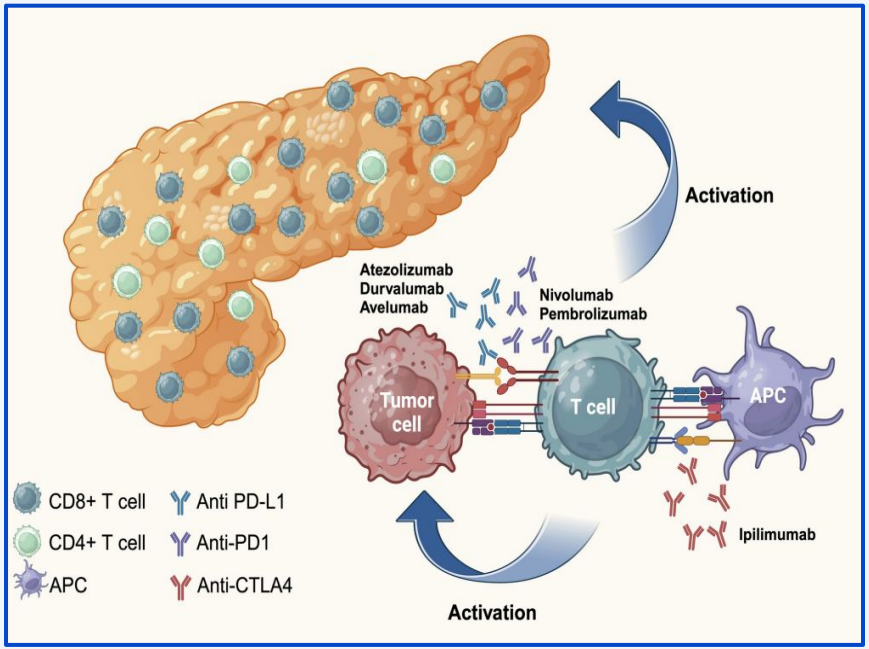

Figure 3 from Immune Checkpoint Inhibitors in Cancer Treatment and Incidence of Pancreatitis. Cureus. 2024 Aug 28;16(8):e68043. doi: 10.7759/cureus.68043. PMID: 39347217; PMCID: PMC11433468.

*irAEs: Immune-related adverse events
Type 3 AIP credit - Dr. Suresh Chari

Type 3 AIP: ICI Induced

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- Pancreatic injury of all ICI-treated patients- **0.6-4% (rare)**, true pancreatitis- **1.9% (rarer)**
- Occur during treatment (also seen upto 12 months following therapy discontinuation)
- Asymptomatic, high levels of lipase/amylase estimated at **2.7%**
- Imaging findings- rare (some diffuse or focal enlargement, pancreatic masses described)

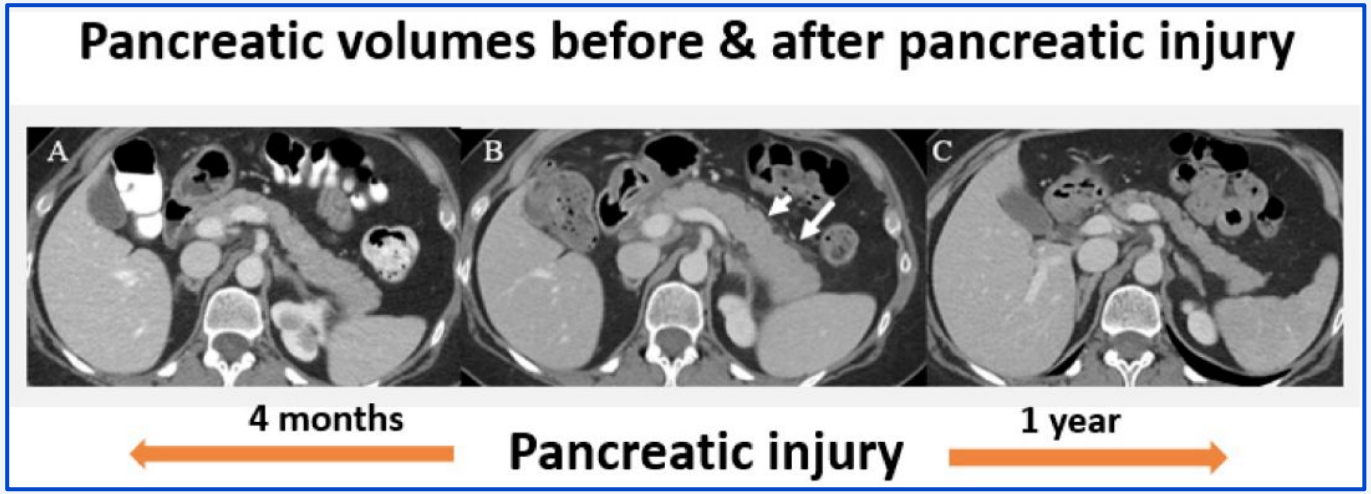

Figure 2 from Autoimmune Pancreatitis: A Review. J. Clin. Med. 2025, 14, 3076. https://doi.org/10.3390/jcm14093076
Abu-Sbeih, J Immunother Cancer 2019; Das, Eur J Radiol, 2020; Johnson Nature Rev Clinical Oncology 2022

Summary: Type 2 & Type 3 AIP

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TYPE 2 AIP (IDCP)

- Rare, Pancreas isolated
- ~35% patients have IBD
- Highly steroid responsive
- Prednisone 20 mg daily × 4 weeks, taper by 5 mg/week
- Low relapse rate (<10%)

TYPE 3 AIP (ICI-PANCREATITIS)

- Very rare, Immune mediated
- No specific treatment for ASYMPTOMATIC high levels of amylase/lipase or mild symptoms
- For symptomatic pancreatitis:
  - Treat with- IV fluids, pain management
  - ***Avoid*** steroids & ICI-therapy ***discontinuation (unless severe)*** as this can impact cancer treatment outcomes

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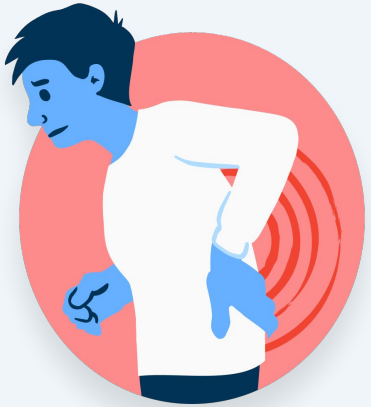
Summary Overview

Pancreas: Exocrine tissue (~ 98%), makes enzymes; Endocrine tissue (~ 2%), secretes insulin & other hormones

SYMPTOMS	TYPE 1 AIP	TYPE 2 AIP	TYPE 3 AIP
Abdominal Pain	🟣 Rare, mild	✅ Common, acute	🟡 May occur
Sudden Pain (radiating to the back), Nausea, Vomiting	🟡 May occur	✅ Common	🟡 May occur
Weight loss, Fatigue, Poor appetite	✅ Common	✅ Common	✅ Common
Jaundice (bile duct involvement)	✅ Common	🟡 May occur	🟡 May occur
EPI: Greasy, loose, smelly stools, diarrhea, bloating, flatulence (exocrine damage)	✅ Common	🟡 May occur	🟡 May occur
Diabetes: New onset or worsening (endocrine damage)	✅ Common	🟡 May occur	🟡 May occur
Other organ involvement symptoms	✅ Common	❌ Not seen	🟡 May occur
Mimics Pancreatic Cancer	✅ Common	🟡 May occur	❌ Not reported



Note: Symptoms vary by type & may be mild, severe, or silent. May also overlap with other forms of pancreatitis & GI diseases delaying diagnosis!

Pancreatitis & EPI

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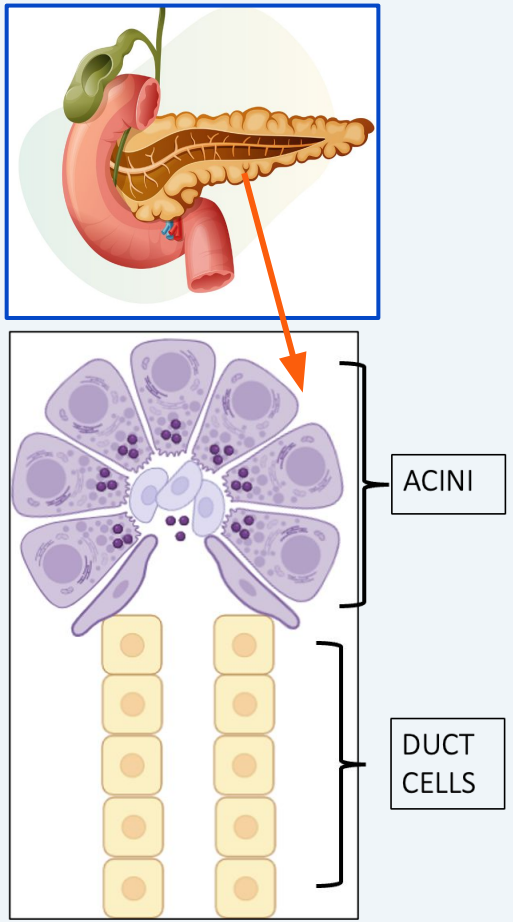
Pancreatitis + EPI* = Significant Disease Burden
Malnutrition, Maldigestion, Malabsorption = Nutritional deficiencies

- ~ 15% CP patients have EPI (35-75% risk of developing EPI)
- ~ 60% of Type 1 AIP patients have or will develop EPI

EPI Diagnosis & Treatment

- Screen for symptoms (oily stools, weight loss, bloating, etc)
- Stool based tests (fecal elastase/ 72-hour fecal fat test)
- Check micronutrient deficiencies (Vitamin A, E, D, K, B12, zinc, copper, selenium, folate & iron)
- DEXA scan screening for metabolic bone disease
- Treat with pancreatic enzyme replacement therapy (PERT) + nutritional management (diet & lifestyle)



*EPI: Exocrine Pancreatic Insufficiency

Whitcomb, AGA-PancreasFest Joint Symposium, Gastro Hep Advances 2023

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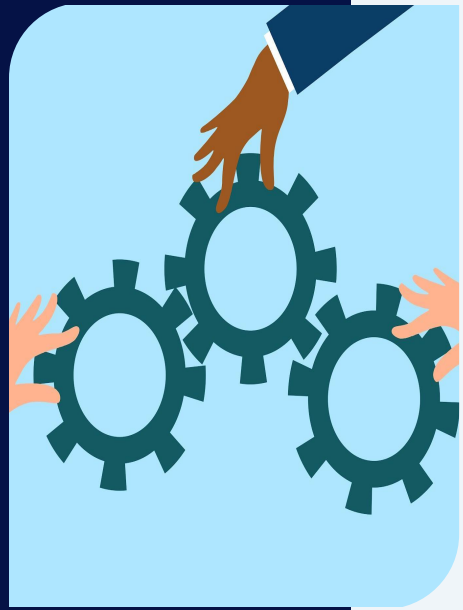
Pancreatitis Treatment Approach



Best Care with Multidisciplinary Team!

- Gastroenterologist/Pancreatologist, Rheumatologist, Neuro Ophthalmologists, Nephrologists (if Type 1 AIP/IgG4-RD), Endocrinologist, Pain specialists, Surgeons, Oncologist (as needed)
- Dietician, Certified Diabetes Educator (CDE), ACPs*, NPs*, Mental health professionals

Exocrine Pancreatic Insufficiency is Common

- Screen for EPI if untreated & treat with PERT
- Assess malabsorption symptoms/PERT dosing/PERT failure (?)

Additional Screening & Management

- Micronutrient deficiencies (Vitamin A, E, D, K, B12, folate, magnesium, selenium, zinc, iron)- Once/Year
- Diabetes (Hba1c)- Once/Year
- Metabolic bone disease- DEXA scan at baseline + Once/2 years

*ACP- Advanced Care Providers * NP- Nurse Practitioners

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Resources

1. Autoimmune Pancreatitis Webpage- Newly Published!
2. AIP Short Form Video & Blog Link: Blog includes list of US AIP-experienced physicians Dr. Hernandez-Barco recommends
3. FDA-approved treatment Inebilizumab (Uplizna) Blog Link
4. FDA Approval of drug for IgG4RD diseases (including type 1 AIP): Amgen Press Release
5. Information about Access to Investigational Medicine for Inebilizumab outside USA
6. IgG4ward Foundation Website
7. IgG4-RD Educational Resources & Physician List/Network (IgG4RD experience)

Designed by Freepik

*Resources shared here will be posted on Mission: Cure's website with the webinar recording

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Patient Advocacy, Community & Resources

Katharine M. Provencher, MSW

Caregiver
Director of Advocacy & Community Engagement
IgG4ward!

IgG4ward!

My Why

Mission:Cure

Roles

- Caregiver, Wife, Mom of 3
- Social worker- 20 years advocacy* experience
- Director of Advocacy & Community Engagement at IgG4ward!

IgG4ward! Foundation

- Founded by Dr. John Stone in November 2023
- IgG4ward! is the 1st International Patient Organization focused only on IgG4-related disease

*Patient advocacy: Supporting & empowering patients to ensure their rights, needs, & preferences are respected and represented in healthcare

IgG4-RD Patient Journey

Mission:Cure

- A chronic, immune-mediated condition: Can affect nearly any organ system
- Type 1 AIP: A manifestation of IgG4-RD
- Many patients initially receive a misdiagnosis, including - pancreatic cancer
- Unnecessary surgeries or treatment delays
- Long diagnosis path: Multiple specialists, tests & emotional strain
- Living with AIP & IgG4-RD means managing a lifelong condition with flares, treatments & frequent monitoring

Kim, IgG4RD Warrior receives infusion treatment

Caregiver Experience

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- For many, diagnosis comes after months—or years—of uncertainty
- Tracking labs, manage appointments, ask the hard questions
- Navigate a complex system that doesn't recognize rare disease
- Caregivers carry fear, grief, & advocacy fatigue
- But also discover strength, connection, & resilience

Image credit: Adapted from Freepik

As advocates, we speak up for those who feel unseen- including families affected by AIP

About IgG4ward!

Mission:Cure

Mission: To Support, Educate, Advocate, Advance Research

Here for everyone impacted by IgG4-RD

- ➔ Sharing trusted, up-to-date info on IgG4-RD
- ➔ Offering practical resources for patients, caregivers, healthcare providers & researchers
- ➔ Creating a strong, supportive online community

Resources: Webinars & Fireside Chats I Mental Health & Caregiver Resources

JAM Video 7 - Avoiding the Side Effects of Treatment: Steroids, B-Cell Depletion|Dr. John Stone

Fireside Chat: Nutrition and IgG4-RD

Caregivers Conversation

IgG4ward! Offers

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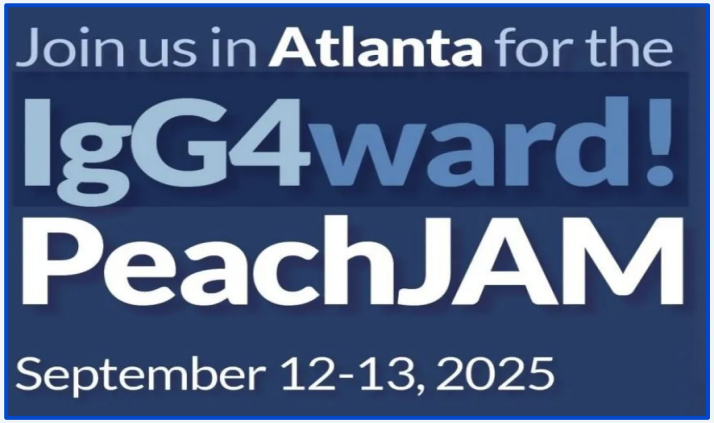
Resources: Physician Network I Annual Patient Jamborees I IgG4ME! app



Stay Connected

➔ **Website:**
igg4ward.org

➔ **Sign up for *The IgG4ward! News***
(quarterly newsletter)

Voices from the Community

Mission:Cure

I was told it was cancer—it wasn't.

I had my pancreas removed for nothing...

The doctors need more information!!

I wish they had tested for IgG4 sooner.

Patients & families value:

- ★ Being believed
- ★ Timely, accurate diagnosis
- ★ Trusted resources
- ★ A community that understands

Join our online community & connect with other IgG4RD Warriors!

IgG4ward!

PAVING A PATH 4WARD

Thank You & Keep in Touch!

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For questions or comments please email:
info@mission-cure.org

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pancreatitis-support