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Chronic Pancreatitis Registry

12th November 2016 Budapest







Biobank and Registry for Pancreatic Patients

Centers contributing to the NEW registry:

Intézmény	Feltöltések száma
SZTE I. sz. Belgyógyászati Klinika	27
Moscow Clinical Scientific Center	25
PTE KK I. sz. Belgyógyászati Klinika	10
SZTE ÁOK Sebészeti Klinika	8
SE I. sz. Sebészeti Klinika	5
PTE KK Sebészeti Klinika	4
Semashko Central Clinical Hospital	4
Betegápoló Irgalmasrend Budailrgalmasrendi Kórház	3
Fejér Megyei Szent György Kórház	3
Réthy Pál Kórház-Rendelőintézet	3
BAZ Megyei Kórház és Egy. Oktató Kórház	2
DEOEC Sebészeti Intézet	2
Petz Aladár Megyei Kórház	2
Bács-Kiskun Megyei Kórház	1
Bajcsy-Zsilinszky Kórház	1
DEKK Belgyógyászati Intézet B. ép. Gasztroenterológia	1
Heim Pál Gyermekkórház	1
	102







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Publication based on the CP registry and biobank:

CP Cohort

Ákos Szücs et al.: Chronic pancreatitis. Multicentre prospective data collection and analysis by the Hungarian Pancreatic Study Group.

under submission

Genetic Studies

Anita Balázs et al.: Genetic analysis of the bicarbonate secreting anion exchanger SLC26A6 in chronic pancreatitis

Anita Balázs et al.: SPINK1 Promoter Variants in Chronic Pancreatitis

Colaboration based on the registry and biobank

Characterization of the molecular basis of familial chronic pancreatitis using the next generation sequencing. (Agnieszka Rygiel)







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Difficulties of data collection

- Characteristics of CP
 - Progressive inflammatory disease of the pancreas
 - Characterized by irreversible morphologic changes
 - Loss of exocrine and endocrine function results from parenchymal fibrosis

Multidisciplinary contribution in life long therapy

- Way of data collection
 - Data collection at a defined point of a chronic disease
 - General (stable) informations: epidemiological data, co-morbidities, ethiology etc.
 - Individual (variable) informations: THERAPY/INTERVENTIONS
 - A single intervention is irrelevant alone
 - Previous and following informations are also required







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NEW REGISTRY









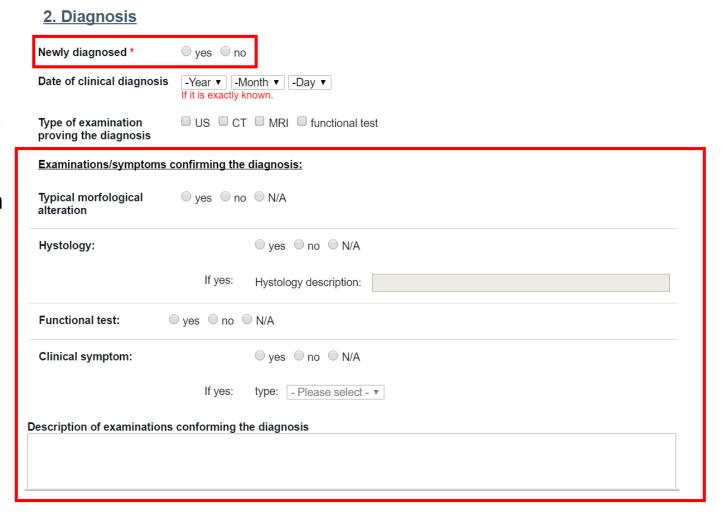
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NEW REGISTRY

Completely new registry for newly diagnosed chronic pancreatitis

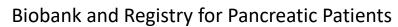
• Real **prospective** data collection

Thorough **diagnosis** based on the followings...





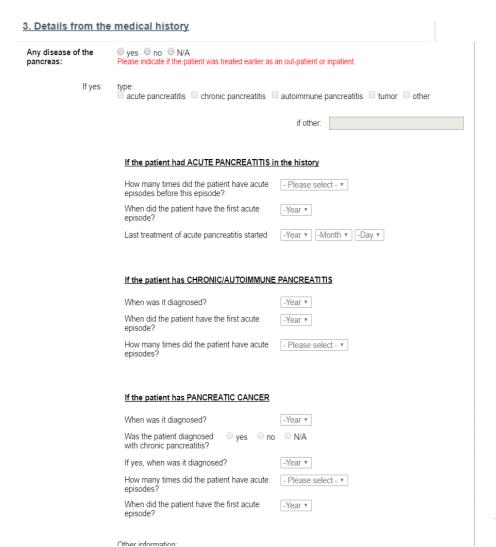






NEW REGISTRY

Medical history



Were there any endoscopic intervention?	○ yes ○ no ○ N/A			
If yes:	type: ERCP endobiliary stent pancreas stent cysta drainage			
	How many times:			
	Early complications			
	Early - Please select - ▼ complicationsPlease indicate only early complication shortly after the intervention.			
	<u>Later complications</u>			
	pancreatic - Please select - * biliary - Please select - *			
	affecting - Please select - * affecting other organs			
Were there any surgical intervention?	⊚ yes			
If yes:	type decompression surgery drainage surgery resection billiodigestive anastomosis hybrid surgery other			
	How many times:			
	Early complications			
	Early - Please select - ▼ complication \$Please indicate only early complication shortly after the intervention.			
	<u>Later complications</u>			
	pancreatic - Please select - *			
	biliary - Please select - * affecting - Please select - * other organs			







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NEW REGISTRY

Etiology

4. Etiology

The answer is "yes" if the etiological factor is proved, the answer	r is "no" if the etiological factor can be ruled out, the answer is "no
data" if the etiological factor was not examined. Please answer	'yes" to " Idiopathic" if etiological factor was not identified.

	If yes: please describe:
Other:	○ yes ○ no
Idiopathic	○ yes ○ no ● N/A
Genetic	yes
Cystic fibrosis	○ yes ○ no ● N/A
Obstruktív	○ yes ○ no ● N/A
Recurrent acute episodes	 yes ○ no ● N/A If this is the cause of chronic pancreatitis.
Autoimmun	○ yes ○ no ● N/A
Virus infection	○ yes ○ no ● N/A
Alcohol	○ yes ○ no ● N/A







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NEW REGISTRY

Imaging

Characteristic morphological changes according to the Cambridge classification

3. Imaging examinations	○ ye	s [©] no		
US/CT/MRI				
Wirsung dilatation/Obstruction	0 yes	⊚ no ⊚ N/A		
Biliary dilatation	0 yes	○ no ○ N/A		
Cholecystolithiasis	0 yes	○ no ○ N/A		
Adenomegalia (>2x)	0 yes	⊙ no ⊙ N/A		
Pseudocysta formation	O yes	○ no ○ N/A		
Calcification	0 yes	○ no ○ N/A		
Abdominal ultrasonography:		Oyes Ono		
If y	es:	Description:		
				11
Abdominal X-ray:		○ yes ○ no		
lf y	es:	Description:		
Chest X-ray:		O yes O no		
lf y	es:	Description:		
				11
Chest Computed Tomography:		O yes O no		
lfy	es:	Description:		
				1
Abdominal Computed Tomography	:	○ yes ○ no		
lf y	es:	Description:		
/				

ERCP/MRCP (diagnostic)
Main duct
Branch ducts less than 3 abnormal branch ducts more than 3 abnormal branch ducts
Biliary duct dilatation
Other alterations
ERCP (diagnostic):
If yes: Description:
MRCP: © yes © no
If yes: Description:
//
<u>EUS</u>
Adenomegalia (>2x)
Echodens laesions
Pseudocysta formation
Abnormality of ducts ○ yes ○ no ○ N/A
Biliary obstruction O yes O no O N/A
EUS: © yes © no
If yes: Description:

Hungarian Pancreatic Study Group – Eastern and Central European Pancreatic Study Groups





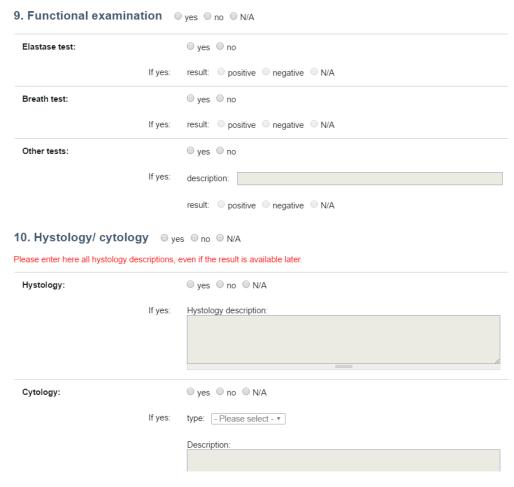


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NEW REGISTRY

Functional examination

Citology/histology









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NEW REGISTRY

Genetics

11. Genetic testing						
Has it been performed earlier:	○ yes ○ no ○ N/A					
If yes	: please describe:					
	results					
	Genes	N/A	Pos	Neg	Results	
	PRSS1	•				
	SPINK1					
	CTRC	•				
	CFTR	•				
	CPA1	•				



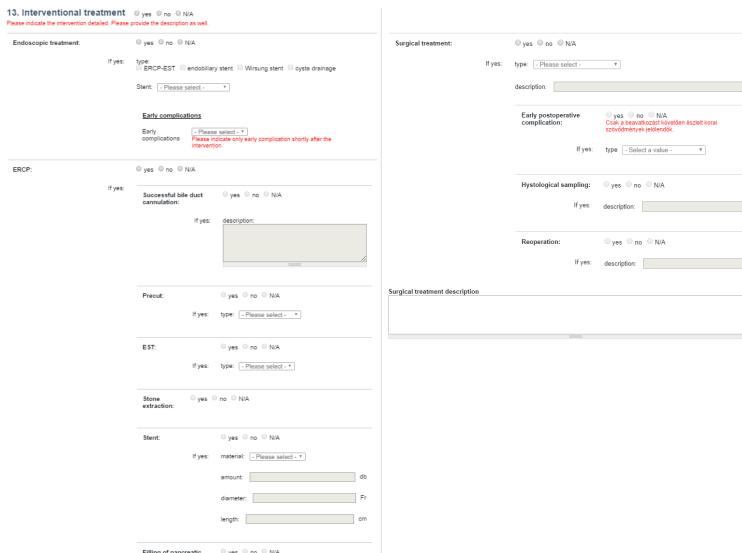




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NEW REGISTRY

- Conservative therapy
- Interventions





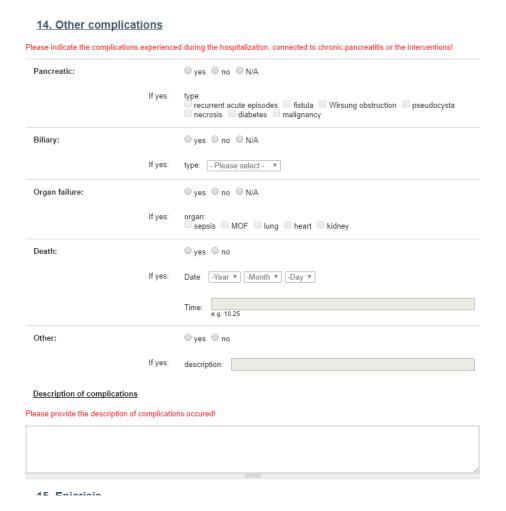




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NEW REGISTRY

Complications









CONCLUSIONS

Prospective multicentric cohort with developed data colletion







Future plans

Further observational studies are required







Thank you for your attention!

The hungarian pancreatic study group is committed to improving the lives of patients suffering from pancreatic diseases.

www.pancreas.hu

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