



Chronic Pancreatitis

Biobank and Registry for Pancreatic Patients



Ákos Szücs

First Department of Surgery, Semmelweis University, Budapest
Hungarian Pancreatic Study Group

Chronic Pancreatitis Registry

12th November 2016
Budapest



Chronic Pancreatitis

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 Gyermekkorház	1
	102



Chronic Pancreatitis

Biobank and Registry for Pancreatic Patients



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)



Chronic Pancreatitis

Biobank and Registry for Pancreatic Patients



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, etiology etc.
 - Individual (**variable**) informations: THERAPY/INTERVENTIONS
- **A single intervention is irrelevant alone**
- **Previous and following informations are also required**



Chronic Pancreatitis

Biobank and Registry for Pancreatic Patients



NEW REGISTRY



- Registry for Pancreatic Patients - Login
- Introduction
- Registry for Pancreatic Patients
- Studies
- Guidelines
- Conferences
- Publications

[Home](#) » [Registry for Pancreatic Patients - Login](#)

Registry for Pancreatic Patients - Login

Please upload Acute Pancreatitis (AP), Chronic Pancreatitis (CP) and Pancreatic Cancer (PC) data to the Registry for Pancreatic Patients webpage!

Please upload Autoimmun Pancreatitis (AIP) data to our former registry page.

[Registry for Pancreatic Patients - Login](#)

[Former registry - Login](#)

NEW REGISTRY

Completely new registry for newly diagnosed chronic pancreatitis

- Real **prospective** data collection

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

2. Diagnosis

Newly diagnosed *

☐ yes ☐ no

Date of clinical diagnosis

-Year ▼ -Month ▼ -Day ▼

If it is exactly known.

Type of examination
proving the diagnosis

☐ US ☐ CT ☐ MRI ☐ functional test

Examinations/symptoms confirming the diagnosis:

Typical morfological
alteration

☐ yes ☐ no ☐ N/A

Hystology:

☐ yes ☐ no ☐ N/A

If yes:

Hystology description:

Functional test:

☐ yes ☐ no ☐ N/A

Clinical symptom:

☐ yes ☐ no ☐ N/A

If yes:

type:

- Please select - ▼

Description of examinations conforming the diagnosis



Chronic Pancreatitis

Biobank and Registry for Pancreatic Patients



NEW REGISTRY

- Medical history

3. Details from the medical history

Any disease of the pancreas:

☐ yes ☐ no ☐ N/A

Please indicate if the patient was treated earlier as an out-patient or inpatient.

If yes:

type:

☐ acute pancreatitis ☐ chronic pancreatitis ☐ autoimmune pancreatitis ☐ tumor ☐ other

if other:

If the patient had ACUTE PANCREATITIS in the history

How many times did the patient have acute episodes before this episode?

- Please select -

When did the patient have the first acute episode?

-Year

Last treatment of acute pancreatitis started

-Year -Month -Day

If the patient has CHRONIC/AUTOIMMUNE PANCREATITIS

When was it diagnosed?

-Year

When did the patient have the first acute episode?

-Year

How many times did the patient have acute episodes?

- Please select -

If the patient has PANCREATIC CANCER

When was it diagnosed?

-Year

Was the patient diagnosed with chronic pancreatitis?

☐ yes ☐ no ☐ N/A

If yes, when was it diagnosed?

-Year

How many times did the patient have acute episodes?

- Please select -

When did the patient have the first acute episode?

-Year

Other information:

If the patient had pancreatic disorder in the medical history

Please indicate the number of previous interventions and accompanying complications.

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 complications

- Please select -
Please indicate only early complication shortly after the intervention.

Later complications

pancreatic

- Please select -

biliary

- Please select -

affecting other organs

- Please select -

Were there any surgical intervention?

☐ yes ☐ no ☐ N/A

If yes:

type:

☐ decompression surgery ☐ drainage surgery ☐ resection ☐ biliodigestive anastomosis ☐ hybrid surgery ☐ other

How many times:

Early complications

Early complications

- Please select -
Please indicate only early complication shortly after the intervention.

Later complications

pancreatic

- Please select -

biliary

- Please select -

affecting other organs

- Please select -

Pancreas disorders in family history: ☐ yes ☐ no ☐ N/A

NEW REGISTRY

- Etiology**

4. Etiology

The answer is "yes" if the etiological factor is proved, the answer 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.

- Alcohol ☐ yes ☐ no ☒ N/A
- Virus infection ☐ yes ☐ no ☒ N/A
- Autoimmun ☐ yes ☐ no ☒ N/A
- Recurrent acute episodes ☐ yes ☐ no ☒ N/A
If this is the cause of chronic pancreatitis.
- Obstruktív ☐ yes ☐ no ☒ N/A
- Cystic fibrosis ☐ yes ☐ no ☒ N/A
- Genetic ☐ yes ☐ no ☒ no tests were made
- Idiopathic ☐ yes ☐ no ☒ N/A

Other: ☐ yes ☐ no

If yes: please describe:

NEW REGISTRY

• Imaging

Characteristic morphological changes according to the Cambridge classification

8. Imaging examinations ☐ yes ☐ no

US/CT/MRI

- Wirsung dilatation/Obstruction ☐ yes ☐ no ☐ N/A
 Biliary dilatation ☐ yes ☐ no ☐ N/A
 Cholecystolithiasis ☐ yes ☐ no ☐ N/A
 Adenomegalia (>2x) ☐ yes ☐ no ☐ N/A
 Pseudocysta formation ☐ yes ☐ no ☐ N/A
 Calcification ☐ yes ☐ no ☐ N/A

Abdominal ultrasonography: ☐ yes ☐ no

If yes: Description:

Abdominal X-ray: ☐ yes ☐ no

If yes: Description:

Chest X-ray: ☐ yes ☐ no

If yes: Description:

Chest Computed Tomography: ☐ yes ☐ no

If yes: Description:

Abdominal Computed Tomography: ☐ yes ☐ no

If yes: Description:

ERCP/MRCP (diagnostic)

- Main duct ☐ normal ☐ pathologic (obstructed, uneven)
 Branch ducts ☐ less than 3 abnormal branch ducts ☐ more than 3 abnormal branch ducts
 Biliary duct dilatation ☐ yes ☐ no ☐ N/A
 Other alterations

ERCP (diagnostic): ☐ yes ☐ no

If yes: Description:

MRCP: ☐ yes ☐ no

If yes: Description:

EUS

- Adenomegalia (>2x) ☐ yes ☐ no ☐ N/A
 Echodens lesions ☐ yes ☐ no ☐ N/A
 Pseudocysta formation ☐ yes ☐ no ☐ N/A
 Abnormality of ducts ☐ yes ☐ no ☐ N/A
 Biliary obstruction ☐ yes ☐ no ☐ N/A

EUS: ☐ yes ☐ no

If yes: Description:



Chronic Pancreatitis

Biobank and Registry for Pancreatic Patients



NEW REGISTRY

- Functional examination

9. Functional examination ☐ yes ☐ no ☐ N/A

Elastase test: ☐ yes ☐ no

If yes: result: ☐ positive ☐ negative ☐ N/A

Breath test: ☐ yes ☐ no

If yes: result: ☐ positive ☐ negative ☐ N/A

Other tests: ☐ yes ☐ no

If yes: description:

result: ☐ positive ☐ negative ☐ N/A

10. Hystology/ cytology ☐ yes ☐ no ☐ N/A

Please enter here all hystology descriptions, even if the result is available later.

Hystology: ☐ yes ☐ no ☐ N/A

If yes: Hystology description:

Cytology: ☐ yes ☐ no ☐ N/A

If yes: type:

Description:

- Citology/histology



Chronic Pancreatitis

Biobank and Registry for Pancreatic Patients



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	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	
SPINK1	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	
CTRC	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	
CFTR	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	
CPA1	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	
	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	



Chronic Pancreatitis

Biobank and Registry for Pancreatic Patients



NEW REGISTRY

- Conservative therapy
- Interventions

13. Interventional treatment

☐ yes ☐ no ☐ N/A

Please indicate the intervention detailed. Please provide the description as well.

Endoscopic treatment:

☐ yes ☐ no ☐ N/A

If yes:

type:

☐ ERCP-EST ☐ endobiliary stent ☐ Wirsung stent ☐ cysta drainage

Stent:

- Please select -

Early complications

Early complications

- Please select -

Please indicate only early complication shortly after the intervention.

ERCP:

☐ yes ☐ no ☐ N/A

If yes:

Successful bile duct cannulation: ☐ yes ☐ no ☐ N/A

If yes:

description:

Precut:

☐ yes ☐ no ☐ N/A

If yes:

type: - Please select -

EST:

☐ yes ☐ no ☐ N/A

If yes:

type: - Please select -

Stone extraction:

☐ yes ☐ no ☐ N/A

Stent:

☐ yes ☐ no ☐ N/A

If yes:

material: - Please select -

amount:

db

diameter:

Fr

length:

cm

Filling of pancreatic

☐ yes ☐ no ☐ N/A

Surgical treatment:

☐ yes ☐ no ☐ N/A

If yes:

type:

- Please select -

description:

Early postoperative complication:

☐ yes ☐ no ☐ N/A

Csak a beavatkozást követően észlelt korai szövődmények jelölendők.

If yes:

type:

- Select a value -

Hystological sampling:

☐ yes ☐ no ☐ N/A

If yes:

description:

Reoperation:

☐ yes ☐ no ☐ N/A

If yes:

description:

Surgical treatment description

NEW REGISTRY

- Complications**

14. Other complications

Please indicate the complications experienced during the hospitalization, connected to chronic pancreatitis or the interventions!

Pancreatic:	<input type="radio"/> yes <input type="radio"/> no <input type="radio"/> N/A
If yes:	type: <input type="checkbox"/> recurrent acute episodes <input type="checkbox"/> fistula <input type="checkbox"/> Wirsung obstruction <input type="checkbox"/> pseudocysta <input type="checkbox"/> necrosis <input type="checkbox"/> diabetes <input type="checkbox"/> malignancy
Biliary:	<input type="radio"/> yes <input type="radio"/> no <input type="radio"/> N/A
If yes:	type: <input type="text" value="- Please select -"/>
Organ failure:	<input type="radio"/> yes <input type="radio"/> no <input type="radio"/> N/A
If yes:	organ: <input type="checkbox"/> sepsis <input type="checkbox"/> MOF <input type="checkbox"/> lung <input type="checkbox"/> heart <input type="checkbox"/> kidney
Death:	<input type="radio"/> yes <input type="radio"/> no
If yes:	Date: <input type="text" value="-Year"/> <input type="text" value="-Month"/> <input type="text" value="-Day"/> Time: <input type="text"/> e.g. 10:25
Other:	<input type="radio"/> yes <input type="radio"/> no
If yes:	description: <input type="text"/>

Description of complications

Please provide the description of complications occurred!

15. Exacerbation



Chronic Pancreatitis

Biobank and Registry for Pancreatic Patients



CONCLUSIONS

Prospective multicentric cohort with developed data collection



Chronic Pancreatitis

Biobank and Registry for Pancreatic Patients



Future plans

Further observational studies are required



Chronic Pancreatitis

Biobank and Registry for Pancreatic Patients



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

Sponsors of the Conference



BERLIN-CHEMIE
MENARINI



RICHTER GEDEON

