



Acute Pancreatitis

Biobank and Registry for Pancreatic Patients



Szilárd Gódi

Department of Translational Medicine, University of Pécs
Hungarian Pancreatic Study Group

Acute Pancreatitis Registry

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History of the registry

- The Registry for Pancreatic Patients was established to collect data and biological samples from patients with pancreatic diseases for scientific purposes.
- Received the ethical and biobank permission in 2012 (TUKEB-22254-1/2012/EKU and IF 702-19/2012).
- The enrollment of the patients started in 2012.



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Contributing centers

- Since the start 37 Hungarian 23 foreign institutions joined (from 17 countries).
- 32 centers from Hungary and 5 centers from abroad have already uploaded patient forms.
- Until 09/11/2016 **1431 A forms** (patients) were uploaded.



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Top 10 Centers

Hu, Szeged, SZTE I. sz. Belgyógyászati Klinika	266
Hu, Székesfehérvár, Fejér Megyei Szent György Kórház	215
Hu, Pécs, PTE I.sz. Belgyógyászati Klinika	204
Hu, Budapest, Bajcsy-Zsilinszky Kórház	141
Hu, Békéscsaba, Réthy Pál Kórház-Rendelőintézet	60
Hu, Szeged, SZTE II-es Kórház	51
Hu, Szentes, Dr. Bugyi István Kórház, Belgyógyászat	51
Hu, Szeged, SZTE II. sz. Belgyógyászati Klinika	50
Hu, Szeged, SZTE SBO	45
Hu, Gyula, Békés Megyei Pándy Kálmán Kórháza III.sz. Bel/Gasztroenterológia	37



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Enrolled patients

- Patients with acute pancreatitis can be enrolled regardless to their age.
- Patients are allowed to be enrolled upon their informed consent.
- Data can only be recorded from centers who joined the Registry of Pancreatic Patients.



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Recorded data

- Patients are questioned about their medical history, complains and symptoms.
- All these answers and data from their patient files are uploaded.
- Details from their treatment is also recorded (antibiotics, interventios, nutrition).
- Blood samples are collected (after informed consent) for genetic examinatioos.



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Recorded data

- All patients have an A form which contains their medical history, complains and all data from the day of the admission.
- The patients additional reports can also be uploaded on an A form.
- Data from the 2nd day are collected on B forms each days.



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FORM A Admission form

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1. Patient personal details

Insurance number *

Name *

Date of birth * -Year ▼ -Month ▼ -Day ▼

Gender * female male

Race - Please select - ▼

Admission date * -Year ▼ -Month ▼ -Day ▼

Last day of treatment -Year ▼ -Month ▼ -Day ▼

Date of interview 2016 ▼ Nov ▼ 9 ▼

Institute
Hu, Pécs, PTE I.sz.
Belgyógyászati Klinika

Orvos kód
GS

Blood sample code

Date of blood sampling

-Year ▼

-Month ▼

-Day ▼

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2. Details from the medical history

Alcohol
consumption:

yes no

If yes: frequency:

amount (per occasion):

for how many years:

Total alcohol consumption in the last two weeks?:

If not:

Did you drink alcohol
earlier?

yes no N/A

If yes: frequency:

amount (g/occasion):

for how many years:

How long ago did you stop drinking alcohol?:

3. 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.

- Biliary yes no N/A
- Alcohol yes no N/A
- Hypertriglyceridaemia yes no N/A
- Post-ERCP yes no N/A
- Virus infection yes no N/A
- Trauma yes no N/A
- Drug-induced yes no N/A
- Congenital anatomical malformation yes no N/A
- Cystic fibrosis yes no N/A
- Gluten-sensitive enteropathy yes no N/A
- Genetic yes no no tests were made

4. Complains, symptoms

Abdominal pain: yes no

If yes: since when:

type:

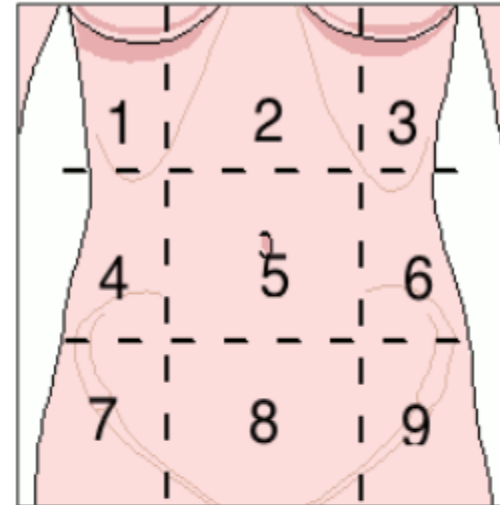
intensity:

Location:

Specify location:

- | | | |
|----------------------------|----------------------------|----------------------------|
| <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 |
| <input type="checkbox"/> 4 | <input type="checkbox"/> 5 | <input type="checkbox"/> 6 |
| <input type="checkbox"/> 7 | <input type="checkbox"/> 8 | <input type="checkbox"/> 9 |

radiation:



Nausea: yes no

Vomiting: yes no



Acute Pancreatitis

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5. Admission details and state

Blood pressure / Hgmm

Heart rate /perc

Body weight kg

Body height cm

Respiratory rate /min

Body temperature (axiliar) °C

Body temperature (rectal) °C

Oxygen saturation %

Previous O₂ therapy yes no N/A

Abdominal tenderness yes no N/A

Abdominal guarding yes no N/A

6. Laboratory parameters

Amylase increased more than 3x yes no N/A

Lipase increased more than 3x yes no N/A

Amylase	<input type="text"/>	U/l
Lipase	<input type="text"/>	U/l
White blood cell (WBC) count	<input type="text"/>	G/l
Red blood cell (RBC) count	<input type="text"/>	T/l
Hemoglobin	<input type="text"/>	g/l Konverzió: mmol/l
Hematocrit	<input type="text"/>	%
Thrombocyte	<input type="text"/>	G/l
Glucose	<input type="text"/>	mmol/l Konverzió: mg/dL
Blood urea nitrogen	<input type="text"/>	mmol/l Konverzió: mg/dL
Creatinine	<input type="text"/>	umol/l Konverzió: mg/dL
eGFR	<input type="text"/>	
C-reactive protein (mg/l)	<input type="text"/>	
ASAT/GOT	<input type="text"/>	U/l

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7. Imaging examinations yes no

Does the patient have pleural fluid yes no N/A

Does the patient have lung infiltrate yes no N/A

Does the patient have abnormal pancreatic structure: yes no N/A

If yes: type:
 hypoechoic hyperechoic peripancreatic fluid
 irregular and blurred contours Wirsung dilatation (above 1mm) ascites
 calcification cyst inhomogeneous structure fatty tissue infiltration
 edematous pancreas enlarged pancreas

Abdominal ultrasonography: yes no

If yes: Description:

Abdominal X-ray: yes no



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8. Interventions – first day yes no

ERCP: yes no

If yes:

Successful bile duct cannulation: yes no N/A

If yes:

description:

Precut: yes no N/A

If yes: type:

EST: yes no N/A

If yes: type:

9.a Intravenous fluid in the first 24 hours

Intravenous fluid in the first 24 hours

ml

To be counted from the first moment until the end of the first 24 hours of medical treatment including ANY KIND of intravenous fluid (e.g. i.v. antibiotics) given by the ambulance, emergency unit and inpatient department.

9.b Immediate therapy on the day of admission

The therapy questions refer to the day of admission from here.

Intravenous fluid: yes no

type of fluid	amount
<input type="text"/>	<input type="text"/> ml
<input type="text"/>	<input type="text"/> ml
<input type="text"/>	<input type="text"/> ml

Parenteral feeding: yes no

formula

amount

12. Complications

Please register pancreatic complication of fluid collection/pseudocyst/necrosis only if you had imaging proof on the day of admission.

Pancreatic: yes no N/A

If yes: type:
 fluid collections pseudocyst necrosis diabetes other

Affecting other organs: yes no

If yes: organ:
 lung heart kidney other

Death: yes no

If yes: the exact time of death:
e.g. 10.25 or 22.45



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15. Severity of pancreatitis

Severity *

- Please select - ▼

Mild acute pancreatitis

- No organ failure
- No local or systemic complications

Moderately severe acute pancreatitis

- Organ failure that resolves within 48 h (transient organ failure) and/or
- Local or systemic complications without persistent organ failure

Severe acute pancreatitis

- Persistent organ failure (>48 h)
- Single organ failure
- Multiple organ failure

Banks PA, Bollen TL, Dervenis C, et al: Classification of acute pancreatitis-2012: revision of the Atlanta classification and definitions by international consensus. Gut 2013; 62: 102-111. doi: 10.1136/gutjnl-2012-302779

Consent form is filled *

I declare that the patient received the necessary information and signed the consent form.

Notes



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Data quality

- We use a four step approval method to maintain good data quality:
 - First step is the local administrator.
 - Second step is the patients' doctor
 - Third step is the supervising administrator
 - Fourth step is the registry PI



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Recorded forms

- **1431 A** forms were recorded.
- **801 A** (56 %) forms have all four approvals.
- **80 A** (5,5 %) forms were rejected.

- **14240 B** forms were recorded.
- **8122 B** (57%) forms have all four approvals.
- **419 B** (2,9 %) forms were rejected .



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Using this huge amount of data we are able to:

- Obtain nearly nation wide information.
- Collect epidemiological data.
- Make groups of patients using filters.
- Analyze the impact of certain treatments.



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Things to do:

- We have to speed up the approvals.
- Recruit new centers.
- Regularly update the registry making it easier to use.
- Maintain high data quality with user guides, trainings and and continuous feedback.



Acute Pancreatitis

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Publication!

RESEARCH ARTICLE

Prospective, Multicentre, Nationwide Clinical Data from 600 Cases of Acute Pancreatitis

Andrea Párniczky¹, Balázs Kui², Andrea Szentesi^{2,3}, Anita Balázs², Ákos Szücs⁴, Dóra Mosztbacher⁵, József Czimmer⁶, Patrícia Sarlós⁶, Judit Bajor⁶, Szilárd Gódi⁶, Áron Vincze⁶, Anita Illés⁶, Imre Szabó⁶, Gabriella Pár⁶, Tamás Takács², László Czakó², Zoltán Szepes², Zoltán Rakonczay², Ferenc Izbéki⁷, Judit Gervain⁷, Adrienn Halász⁷, János Novák⁸, Stefan Crai⁸, István Hritz⁹, Csaba Góg¹⁰, János Sümegi¹¹, Petra Golovics¹², Márta Varga¹³, Barnabás Bod¹⁴, József Hamvas¹⁵, Mónika Varga-Müller³, Zsuzsanna Papp³, Miklós Sahin-Tóth¹⁶, Péter Hegyi^{2,3,17*}, on behalf of the Hungarian Pancreatic Study Group¹



1 Heim Pál Children's Hospital, Budapest, Hungary, **2** First Department of Medicine, University of Szeged, Szeged, Hungary, **3** Institute for Translational Medicine, University of Pécs, Pécs, Hungary, **4** First Department of Surgery, Semmelweis University, Budapest, Hungary, **5** Department of Pediatrics, Balassa János Hospital of County Tolna, Szekszárd, Hungary, **6** First Department of Medicine, University of Pécs, Pécs, Hungary, **7** Szent György University Teaching Hospital of County Fejér, Székesfehérvár, Hungary, **8** Pándy Kálmán Hospital of County Békés, Gyula, Hungary, **9** Bács-Kiskun County University Teaching Hospital, Kecskemét, Hungary, **10** Healthcare Center of County Csongrád, Makó, Hungary, **11** Borsod-

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The screenshot shows a web browser window displaying the website pancreas.hu/en. The page features a navigation menu on the left with items: Registry for Pancreatic Patients - Login, Introduction, Registry for Pancreatic Patients, Studies, Guidelines, Conferences, Publications, Newsletters, and Patient Club. The main content area includes a banner with the HPSG logo and a photograph of a man speaking at a podium. To the right of the photo is a poster for the 3rd Conference of the Hungarian Pancreatic Study Group and the 9th International Symposium on Alcoholic Liver. A blue box highlights the text: "5th Conference of the Hungarian & 3rd Conference of the Eastern and Central European Pancreatic Study Groups". The bottom of the browser window shows the Windows taskbar with the time 23:49 and date 2016.11.09.

If you are interested please visit www.pancreas.hu
Or e-mail us: hspg.info@gmail.com



Acute 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

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