



- 1) In order to participate on the project “Adverse Reactions of Immunoglobulin Therapy in Primary Immunodeficient Patients” you have to access <https://registrolasid.org> and click on  **Projetos** on the link “Efeitos Adversos à Infusão de imunoglobulina Humana em Pacientes com Imunodeficiência Primária”



The screenshot shows the website <https://registrolasid.org>. The header includes the LASID logo (Latin American Society for Immunodeficiencies) and a 'Home' link. A red banner at the top right reads 'Registro on-line de IDPs'. Below this, a section titled 'Os objetivos do registro de pacientes são:' lists seven objectives. A 'Projetos' section is visible, with a red oval highlighting the project titled 'Efeitos adversos à infusão de imunoglobulina humana em pacientes com imunodeficiência primária'.


← → ↻ 🏠 <https://registrolasid.org>

 Home

Registro on-line de IDPs

☰ Os objetivos do registro de pacientes são:

- i. Coletar dados clínicos de pacientes com IDPs;
- ii. Melhorar o diagnóstico;
- iii. Melhorar a classificação;
- iv. Melhorar o prognóstico;
- v. Otimizar a terapia;
- vi. Compilar dados sobre as IDPs;
- vii. Realizar estudos clínicos internacionais e multicêntricos, genéticos e terapêuticos.

 **Projetos**

 "Efeitos adversos à infusão de imunoglobulina humana em pacientes com imunodeficiência primária"

- 2) A new page will be opened where you need to enter the previously acquired login and password with Mr Eiel Gonçalves (lagid.adm@gmail.com).




Immunoglobulin's adverse reactions registry

Login

Username:

Password:

- 3) The list of all your patients previously entered into the LASID registry will be displayed. Click on the icon  in the column "Therapy" . Note that patients need to be previously entered in the LASID registry.












Immunoglobulin's adverse reactions registry

Welcome sartorelli, [logout](#)

Patient List

Show entries

Search:

ID	Place of living	Date of birth (yyyy-mm-dd)	Sex	Therapy
6735	Brazil	2004-1-3	m	 
6876	Brazil	2005-7-26	m	
0003	Brazil	2002-7-20	f	
6884	Brazil	2003-9-7	f	
6885	Brazil	2006-11-6	m	
6886	Brazil	2005-7-26	m	
6886	Brazil	2005-7-26	m	
6887	Brazil	2000-7-21	m	

- 4) The specific questionnaire will be displayed



Immunoglobulin's adverse reactions registry

Welcome sartorelli, [logout](#)

Immunoglobulin Replacement therapy side effects

Adverse Reaction Registry

Patient Identification

Patient ID #6876

Date of Birth

Sex

Current Age (years)

Weight (kg)

Blood-type

5) Choose your's patient diagnosis

Diagnosis

- Ataxia - telangiectasia
- CVID
- HIGM
- CVID
- Specific Antibody Defects with normal immunoglobulin levels
- X-linked agammaglobulinemia
- Wiskott-Aldrich
- Severe combined immunodeficiency
- Other diseases - specify

Please enter your comment here

Age at disease onset (years)

Age at diagnosis (years)

6) Choose all of the immunoglobulin brands your patient **has used in the last six months**, even if there are no adverse effects to report.

Immunoglobulin brands used for treat this patient up to 6 months (please choose all used)

Brands

- Armoglobina P
- Beriglobin
- Carimune
- Endobulin
- Flebogamma 5%
- Flebogamma 10%
- GammagArd
- Hizentra
- Immunoglobulin
- Octagam 5%
- Octagam 10%
- Pentaglobin
- Privigen 10%
- Kiovig 10%
- Sandoglobulin
- Tegeline
- Vigam
- Others

Please enter your comment here

7) For each immunoglobulin brand choosed above a new quiz will be displayed

Immunoglobulin brands side effects (Select at least one brand to see this section)

Others

Was it the first infusion of this immunoglobulin brand?

Yes
 No
 No data

Infusion route?

IV
 SC

g/total

Periodicity?

Twice or more a week
 Once a week
 Every 3 or 4 weeks
 No data

Treatment interruption date?

Reason for interruption?

Side effects
 Lack of availability
 Route of administration exchange
 Another reason
 Unknown

Are there side effects to report?

Yes
 No

8) If you click on “yes” ,there are adverse reactions to report, a new window with questions about the side effects will be opened.

PLEASE ANSWER THE QUESTIONS: 1 TO 5

1. Side Effects

Mild

- Headache
- Migraine
- Flushing
- Back pain
- Myalgia
- Nausea
- Vomiting
- Tachycardia
- Abdominal pain
- Arthralgia
- Anxiety
- Rash
- Urticaria
- Fever
- Malaise
- Irritability

Moderate

- Chest tightness
- Wheezing
- Eczema

Severe

- Hemolysis
- Acute Renal Failure
- Shock
- Heart attack
- Thrombosis
- Anaphylaxis
- Pulmonary embolism
- Aseptic meningitis

2. Treatment of choice

- Oral anti H1 histamines
- Systemic anti H1 histamines
- Oral steroids
- Systemic steroids
- Systemic anti-H2 histamines
- Adrenaline
- Expansion
- Analgesics
- Non-steroidal anti-inflammatory drugs
- No data

3. How was the infusion managed?

- Interrupted
- Temporarily interrupted
- Decreased infusion rate
- Changed immunoglobulin brand
- No data

4. Previous medication

- AntiH1 histamines
- Steroids
- Analgesics
- AntiH2 histamines
- Nonsteroidal anti-inflammatory drugs
- No data

5. Associated risk factors

- Viral Infection
- Fever
- Bacterial infection
- Other factors - specify
- No data

Please enter your comment here

9) Finally there are a few questions about each patient

Others data

Comorbidities

- Chronic lung disease
- Bronchiectasis
- Severe bronchiolitis
- Interstitial lung disease
- Hear failure
- Renal failure
- Diabetes
- Colitis
- Neuropathy
- Unknown

Long term drug use and / or drug prophylactic use

- Antibiotics
- Anti-fungal drugs
- Another
- Unknown

Please enter your comment here

10) For all patients you have already registered in this project a new icon named , will be shown.

To recover or to make any changes to the previously insered data you must click on 





Immunoglobulin's adverse reactions registry

Welcome epnbr, [logout](#)

Patient List

Show entries

Search:

ID	Place of living	Date of birth (yyyy-mm-dd)	Sex	Therapy
53	Brazil	1998-2-2	m	<input type="button" value="New"/>
54	Brazil	1991-8-14	f	<input type="button" value="New"/> 
55	Brazil	1982-3-29	m	<input type="button" value="New"/> 
56	Brazil	1990-10-5	f	<input type="button" value="New"/>