

AL - PID Study

Autoimmune lymphoproliferative primary immunodeficiency

Information Sheet - Follow-up



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Update clinical data - AL- PID study cohort

Your patient has been enrolled into our AL - PID study cohort. Today we kindly ask you to provide us with the follow up information on the CURRENT condition of your patient.

Shipment of blood samples - if possible

- Please send 10 ml - if acceptable - 15 ml EDTA blood and 4 ml serum.
- **Please announce any material > 3 days before sending it.**
(via e-mail or phone, see Lab Contact)
- Send via express (**delivery until 8 am**).
- For patients with German health insurance: please include transfer form (Überweisungsschein) for genetic analysis.
- Please also send the follow up sheet. (IMPORTANT!)

Thank you for your cooperation!

Clinical contact person

Name _____
Phone _____ Fax _____
E-mail _____

Patient label - if applicable

Name of patient

Date of birth
(day/month/year)

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Shipment of

_____ ml EDTA

_____ ml serum

Date of blood sample
day / month / year

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PATIENT INFORMATION

Gender female male

Patient label - if applicable

Name of patient _____

Date of birth (day/month/year)

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NEW INFORMATION

Has any **diagnosis** explaining lymphoproliferation and cytopenia been established?

yes no unknown

If so, please specify: _____

CLINICAL DEVELOPMENT DURING THE LAST 12 MONTHS

Lymphoproliferation

Lymphadenopathy \rightarrow yes no unknown
(> 6 months, > 2 locations)

If yes, current status improved same got worse new occurrence
 current status unknown

Splenomegaly \rightarrow yes no unknown

If yes, current status enlarged (ultrasound investigation) but not palpable
 palpable: cm below ribcage

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 distance unknown
 current status unknown

If yes, current status improved same got worse new occurrence
 current status unknown

Has the patient been **splenectomized**? \rightarrow yes no unknown

If yes, reason for splenectomy _____ (year of splenectomy)
 reason unknown year unknown

Hepatomegaly \rightarrow yes no unknown

If yes, current status enlarged (ultrasound investigation) but not palpable
 palpable: cm below ribcage

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 distance unknown
 current status unknown

If yes, current status improved same got worse new occurrence
 current status unknown

Malignancy \rightarrow yes no unknown

If yes, type of malignancy (e.g. lymphoma) _____ (year of diagnosis)
 type unknown year unknown

AL - PID Study

Follow up Sheet

Patient label - if applicable

Name of patient _____

Date of birth (day/month/year)

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Autoimmunity and infections (during the last 12 months)

Anemia (Hb < 10 g/dl) → yes no unknown

If yes, coomb's positive yes no not done unknown

 requiring immunosuppression / IVIG yes no unknown

Thrombocytopenia (Plt < 100.000/ μ l) → yes no unknown

If yes, anti-platelet antibodies yes no not done unknown

 requiring immunosuppression / IVIG yes no unknown

Neutropenia (ANC < 1000/ μ l) → yes no unknown

If yes, anti-neutrophil antibodies yes no not done unknown

 requiring immunosuppression / IVIG yes no unknown

Autoimmunity and infections (during the last 12 months)

Inflammatory gut disease yes no unknown
(frequent diarrhoea without infectious trigger OR histologic evidence)

Interstitial lung disease yes no unknown
(assessed by CO₂ diffusion capacity OR HRCT)

Bronchiectasis yes no unknown

Inflammatory brain disease yes no unknown
(indicated by MRI AND/OR CSF investigation)

Inflammatory skin disease yes no unknown

Other **autoimmunity / immunodysregulation** yes no unknown
(eg. liver, kidney, thyroid, joints)

If yes, please specify: _____
 autoimmunity / immunodysregulation unknown

Is the patient prone to **infections**? yes no unknown

If yes, bronchopulmonary infections yes no unknown

 candidiasis yes no unknown

 warts yes no unknown

 systemic or chronic viral infections (eg. EBV, CMV, Noro, Adeno) yes no unknown

If yes, please specify: _____
 systemic or chronic viral infections unknown

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Follow up Sheet

Patient label - if applicable

Name of patient _____

Date of birth (day/month/year)

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Hypogammaglobulinemia

yes no unknown

If yes, current **IgG** value

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g/l g/l mg/dl unknown

Hyper-IgM

yes no unknown

If yes, current **IgM** value

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g/l g/l mg/dl unknown

CURRENT SITUATION

Full blood count (determined on the day blood is drawn for diagnostic testing)

Leucocytes

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 / µl unknown

Lymphocytes

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 % unknown

Monocytes

--	--

 % unknown

Is the patient CURRENTLY treated with:

Steroids yes no unknown

Other Immunosuppression yes no unknown

↳ please specify: _____

other immunosuppression unknown

Rituximab (last six months) yes no unknown

↳ Date of the last dose

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 Date unknown
(day/month/year)

IVIg/SCIG yes no unknown

Other specific therapy: _____

Date _____

Signature of Physician _____