FORM B
Follow-up visit

ACROMEGALY REGISTRY
ENDOCRINOLOGY STUDY GROUP

1. Patient personal details

Institute code:

Physician code:

Initials: .....

Number of patient in the registry: .....

Date of visit: .....

↳ **B** 1. / 2. / 3. / 4. / 5. / 6. / 7. / 8. / 9. / 10. / 11. / 12. / 13. / 14. / 15. / 16. / 17. / 18. / 19. / 20. **FORM**

Gender (genetic): female / male

2. Changes in acromegaly-specific medical history

- **Any significant changes or new significant symptoms of acromegaly: yes / no / no data**

- If yes, please specify:

Symptoms of acromegaly severity score

- **Swelling of extremities** yes / no
  - └ If yes, please specify: mild / moderate / severe

- **Excessive sweating and body odor** yes / no
  - └ If yes, please specify: mild / moderate / severe

- **Joint pain** yes / no
  - └ If yes, please specify: mild / moderate / severe

- **Fatigue and muscle weakness** yes / no
  - └ If yes, please specify: mild / moderate / severe

- **Headaches** yes / no
  - └ If yes, please specify: mild / moderate / severe

([*] mild: 1 point, moderate: 2 point, severe: 3 point)

Acromegaly severity score (0-15 point): .....

ACROMEGALY REGISTRY
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- **Enlarged hands:** ☐ Existed symptom: a) No significant changes b) Symptom is over c) Improvement d) Worsening *or* ☐ New significant symptom	- **Deepened voice:** ☐ Existed symptom: a) No significant changes b) Symptom is over c) Improvement d) Worsening *or* ☐ New significant symptom
- **Increase of shoe size:** ☐ Existed symptom: a) No significant changes b) Symptom is over c) Improvement d) Worsening *or* ☐ New significant symptom	- **Husky voice:** ☐ Existed symptom: a) No significant changes b) Symptom is over c) Improvement d) Worsening *or* ☐ New significant symptom
- **Coarsened, enlarged facial features:** ☐ Existed symptom: a) No significant changes b) Symptom is over c) Improvement d) Worsening *or* ☐ New significant symptom	- **Severe snoring:** ☐ Existed symptom: a) No significant changes b) Symptom is over c) Improvement d) Worsening *or* ☐ New significant symptom
- **Coarse, oily, thickened skin:** ☐ Existed symptom: a) No significant changes b) Symptom is over c) Improvement d) Worsening *or* ☐ New significant symptom	- **Impaired vision:** ☐ Existed symptom: a) No significant changes b) Symptom is over c) Improvement d) Worsening *or* ☐ New significant symptom
- **Small outgrowths of skin tissue (skin tags)**: ☐ Existed symptom: a) No significant changes b) Symptom is over c) Improvement d) Worsening *or* ☐ New significant symptom	- **Visual field defects:** ☐ Existed symptom: a) No significant changes b) Symptom is over c) Improvement d) Worsening *or* ☐ New significant symptom
- **Enlarged tongue:** ☐ Existed symptom: a) No significant changes b) Symptom is over c) Improvement d) Worsening *or* ☐ New significant symptom	- **Increased chest size (barrel chest):** ☐ Existed symptom: a) No significant changes b) Symptom is over c) Improvement d) Worsening *or* ☐ New significant symptom
- **Limited joint mobility:** ☐ Existed symptom: a) No significant changes b) Symptom is over c) Improvement d) Worsening *or* ☐ New significant symptom	- **Increased distance between teeth:** ☐ Existed symptom: a) No significant changes b) Symptom is over c) Improvement d) Worsening *or* ☐ New significant symptom

- **Other:** .....

☐ Existed symptom: a) No significant changes
b) Symptom is over
or c) Improvement
d) Worsening

☐ New significant symptom

- **Any significant changes in other symptoms or new significant symptoms: yes / no / no data**

- If yes, please specify:

- **Decreased body and facial hair ♂:** ☐ Existed symptom: a) No significant changes b) Symptom is over *or* c) Improvement d) Worsening ☐ New significant symptom	- **Gynecomastia ♂:** ☐ Existed symptom: a) No significant changes b) Symptom is over *or* c) Improvement d) Worsening ☐ New significant symptom
- **Thinning hair:** ☐ Existed symptom: a) No significant changes b) Symptom is over *or* c) Improvement d) Worsening ☐ New significant symptom	- **Loss of interest in sexual activity:** ☐ Existed symptom: a) No significant changes b) Symptom is over *or* c) Improvement d) Worsening ☐ New significant symptom
- **Erectile dysfunction:** ☐ Existed symptom: a) No significant changes b) Symptom is over *or* c) Improvement d) Worsening ☐ New significant symptom	- **Infertility:** ☐ Existed symptom: a) No significant changes b) Symptom is over *or* c) Improvement d) Worsening ☐ New significant symptom

- **Irregular menstrual periods (oligomenorrhea) or no menstrual periods (amenorrhea) ♀:** ☐ Existed symptom: a) No significant changes b) Symptom is over c) Improvement d) Worsening *or* ☐ New significant symptom	- **Body aches:** ☐ Existed symptom: a) No significant changes b) Symptom is over c) Improvement d) Worsening *or* ☐ New significant symptom
- **Galactorrhea ♀:** ☐ Existed symptom: a) No significant changes b) Symptom is over c) Improvement d) Worsening *or* ☐ New significant symptom	- **Low blood pressure:** ☐ Existed symptom: a) No significant changes b) Symptom is over c) Improvement d) Worsening *or* ☐ New significant symptom
- **Painful intercourse ♀:** ☐ Existed symptom: a) No significant changes b) Symptom is over c) Improvement d) Worsening *or* ☐ New significant symptom	- **Unexplained weight loss:** ☐ Existed symptom: a) No significant changes b) Symptom is over c) Improvement d) Worsening *or* ☐ New significant symptom
- **Acne ♀:** ☐ Existed symptom: a) No significant changes b) Symptom is over c) Improvement d) Worsening *or* ☐ New significant symptom	- **Weight gain:** ☐ Existed symptom: a) No significant changes b) Symptom is over c) Improvement d) Worsening *or* ☐ New significant symptom
- **Hirsutism ♀:** ☐ Existed symptom: a) No significant changes b) Symptom is over c) Improvement d) Worsening *or* ☐ New significant symptom	- **Increased sensitivity to cold:** ☐ Existed symptom: a) No significant changes b) Symptom is over c) Improvement d) Worsening *or* ☐ New significant symptom
- **Lightheadedness:** ☐ Existed symptom: a) No significant changes b) Symptom is over c) Improvement d) Worsening *or* ☐ New significant symptom	- **Constipation:** ☐ Existed symptom: a) No significant changes b) Symptom is over c) Improvement d) Worsening *or* ☐ New significant symptom
- **Fatigue:** ☐ Existed symptom: a) No significant changes b) Symptom is over c) Improvement d) Worsening *or* ☐ New significant symptom	- **Dry skin:** ☐ Existed symptom: a) No significant changes b) Symptom is over c) Improvement d) Worsening *or* ☐ New significant symptom

- **Puffy face:** ☐ Existed symptom: a) No significant changes b) Symptom is over *or* c) Improvement d) Worsening ☐ New significant symptom	- **Depression:** ☐ Existed symptom: a) No significant changes b) Symptom is over *or* c) Improvement d) Worsening ☐ New significant symptom
- **Hoarseness:** ☐ Existed symptom: a) No significant changes b) Symptom is over *or* c) Improvement d) Worsening ☐ New significant symptom	- **Impaired memory:** ☐ Existed symptom: a) No significant changes b) Symptom is over *or* c) Improvement d) Worsening ☐ New significant symptom
- **Decrease in muscle mass:** ☐ Existed symptom: a) No significant changes b) Symptom is over *or* c) Improvement d) Worsening ☐ New significant symptom	- **Difficulty in focusing attention:** ☐ Existed symptom: a) No significant changes b) Symptom is over *or* c) Improvement d) Worsening ☐ New significant symptom
- **Muscle aches, tenderness and stiffness:** ☐ Existed symptom: a) No significant changes b) Symptom is over *or* c) Improvement d) Worsening ☐ New significant symptom	- **Other:** ☐ Existed symptom: a) No significant changes b) Symptom is over *or* c) Improvement d) Worsening ☐ New significant symptom

● Laboratory results

Any significant change in the laboratory results **yes / no**

If yes:

└ GH:

▪ Date of investigation: …. . .. .

- **GH** (baseline, 0 min.):
  - unit: ……. ng/ml ***calculator*** …… mU/L
  - range: ……. - …….

- **GH** (lowest value during an OGTT):
  - unit: ……. ng/ml ***calculator*** ……. mU/L

- range: ……. - …….

└ Other hormones:

- Date of investigation: …. . .. .

- **IGF-1**: - unit: ……. ng/ml ***calculator*** ……. nmol/l
  - Upper limit of normal (ULN): …….
  → Upper limit of normal ratio (ULNR): …….

- **Prolactin**:
  - unit: ……. ng/ml ***calculator*** ……. mU/L
  - range: ……. - …….
- **TSH**:
  - unit: ……. mU/L
  - range: ……. - …….

- **FT_4**:
  - unit: ……. pmol/L ***calculator*** ……. ng/dl
  - range: ……. - …….

- **ACTH**:
  - unit: ……. pmol/L ***calculator*** ……. pg/ml
  - range: ……. - …….

- **Cortisol**:
  - unit: ……. nmol/L ***calculator*** ……. µg/dl
  - range: ……. - …….

- **FSH**:
  - unit: ……. U/L
  - range: ……. - …….

- **LH**:
  - unit: ……. U/L
  - range: ……. - …….

- **Testosterone** ♂:
  - unit: ……. nmol/L ***calculator*** ……. ng/ml
  - range: ……. - …….

- **Estradiol** ♀:
  - unit: ……. pmol/L ***calculator*** ……. pg/ml
  - range: ……. - …….

Biochemical control of acromegaly:

- controlled / partially controlled / uncontrolled / no data

Findings of pituitary insufficiency: **yes / no / no data**

└ **Hypadrenia**

- No significant changes / Finding is over / Improvement / Worsening / No data

or

- New significant finding

- Controlled by treatment: yes / no / not applicable / no data

└ **Hypothyroidism**

- No significant changes / Finding is over / Improvement / Worsening / No data

or

- New significant finding

- Controlled by treatment: yes / no / not applicable / no data

└ **Hypogonadism**

- No significant changes / Finding is over / Improvement / Worsening / No data

or

- New significant finding

- Controlled by treatment: yes / no / not applicable / no data

└ **Diabetes insipidus**

- No significant changes / Finding is over / Improvement / Worsening / No data

or

- New significant finding

- If new significant finding: Excretion of more than 4 liter urine: yes / no / no data

- Controlled by treatment: yes / no / not applicable / no data

● **New radiological image:** yes / no / no data

If yes:

└ Date of imaging: …. . .. . ..

└ Imaging modality: CT / MRI

└ Maximal diameters of the tumor (3D if assessed): ……. x ……. x ……. [mm] / No data.

└ Size category: Micro /Macro / Giant / Not visualized /Empty sella / No data.

└ Sinusoidal invasion: Yes / No / Not known / No data.

└ Optic chiasm: No contact / Contact / Displaced / No data.

└ Ectopic: Yes / No / Not known.

└ Change from the previous investigation: No change / Decreased / Increased / No data.

3. Any significant changes in details from the medical history

yes / no / no data

● **Dysglycemia:**

- No significant changes / Finding is over / Improvement / Worsening / No data

- New significant dysglycemia **yes / no / no data**

└ If yes: - Since when: ……

- Controlled by treatment: yes / no / no data

● **Lipid metabolism disorder:**

- No significant changes / Finding is over / Improvement / Worsening / No data

- New significant disorder of lipid metabolism: **yes / no / no data**

└ If yes: - Since when: ……

- Controlled by treatment: yes / no / no data

● **Hypertension:**

- No significant changes / Finding is over / Improvement / Worsening / No data

- Newly discovered hypertension yes / no / no data
└ If yes: - Since when: ……

- Controlled by treatment: yes / no / no data

● **Cardiomyopathy:**

- Any significant changes in the cardiomyopathy yes / no / no data
└ If yes:
- Changes in the ECG: yes / no / no data
- If yes:
□ Any significant changes in AV conduction abnormality
└ No significant changes / Finding is over / Improvement / Worsening
□ Any significant changes in rhythm abnormality
└ No significant changes / Finding is over / Improvement / Worsening
□ Any significant changes in left ventricular hypertrophy
└ No significant changes / Finding is over / Improvement / Worsening
□ Any significant changes in bundle branch block
└ No significant changes / Finding is over / Improvement / Worsening
□ Any significant changes in ischemic lesion
└ No significant changes / Finding is over / Improvement / Worsening
□ Any significant changes in QTc prolongation
└ No significant changes / Finding is over / Improvement / Worsening
□ Any significant changes in other: ….
└ No significant changes / Finding is over / Improvement / Worsening
- Any significant changes in echocardiography: yes / no / no data
If yes: - date of examination: …. . .. .
- EF [%]: …….
└ No significant changes / Finding is over / Improvement / Worsening
- Any significant changes in degree of left ventricular hypertrophy:
└ No significant changes / Finding is over / Improvement / Worsening
- Heart failure: yes / no / no data

└ No significant changes / Finding is over / Improvement / Worsening / No data.
└ Highest NYHA grade (I-IV): …….

- New cardiomyopathy **yes / no / no data**
└ If yes:
- Since when: ……..
- ECG abnormality: yes / no / no data
- If yes:
□ AV conduction abnormality
□ Rhythm abnormality
□ Left ventricular hypertrophy
□ Bundle branch block
□ Ischemic lesion
□ QTc prolongation
□ Other: ….
- Echocardiography: yes / no / no data
If yes: - date of examination: …. . .. . ..
- EF [%]: …….
- Degree of left ventricular hypertrophy:
no / mild /moderate /severe.
- Heart failure: yes / no
If yes: - Since when: ……..
- Required hospitalization: yes / no
- Highest NYHA grade (I-IV): ……

- Controlled by treatment: yes / no / not applicable / no data

● **Sleep apnoe:**

- No significant changes / Finding is over / Improvement / Worsening / No data

- Any new sleep apnoe: **yes / no / no data**
└ If yes: - When was discovered: ……..

- Controlled by treatment: yes / no / not applicable / nincs adat

● **Stroke:**

- No significant changes / Finding is over / Improvement / Worsening / No data

- Any new stroke: **yes / no / no data**
└ If yes: - When was discovered: ……

● **Renal failure:**

- No significant changes / Finding is over / Improvement / Worsening
  - Lowest eGFR [ml/min/1.73m^2]: …….

- Any new significant renal failure: yes / no / no data
└ If yes: - Since when: ……..
- Lowest eGFR [ml/min/1.73m^2]: …….

- Controlled by treatment: yes / no / not applicable

● **Malignant tumor**

- No significant changes / Disease is over / Improvement / Worsening / No data

- Any new malignant tumor: yes / no / no data
└ If yes, type:
Brain tumor / Thyroid gland tumor / Gastrointestinal tumor / Hematological tumor / Tumor of the skin and-or soft tissue / Urological tumor / Gynecological tumor / Breast cancer / Other (please describe): ……..
└ When was discovered (year): ……..

- Controlled by treatment: yes / no / not applicable / no data

● **Colonic polyp(s):**

- No significant changes / Finding is over / Improvement / Worsening / No data

- Any new colonic polyp(s): yes / no /not known / no data
└ If yes: - When was discovered: ……..

- Controlled by treatment: yes / no / not applicable / no data

● **Other, benign tumor:**

- No significant changes / Finding is over / Improvement / Worsening / No data

- Any new other, benign tumor: yes / no / no data
└ If yes: - When was discovered: ……..

- Controlled by treatment: yes / no / not applicable / no data

● **Carpal tunnel syndrome:**

- No significant changes / Finding is over / Improvement / Worsening / No data

- Any new carpal tunnel syndrome: **yes / no / no data**
└ If yes: - Since when: ……..

- Controlled by treatment: yes / no / not applicable / no data

● **Bone disorder:**

- No significant changes / Disorder is over / Improvement / Worsening / No data

- New significant changes in bone disorder: **yes / no / no data**
└ If yes: - Since when: ……..
- DEXA: yes /no / no data
└ If yes: lumbal / femoral / other.
- Other: ……
└ T-score: …….
└ Z-score: …….

● **Fracture(s):**

- No significant changes / Disorder is over / Improvement / Worsening / No data

- Any new fracture(s): **yes / no / no data**
└ If yes: - When happened: ……..
- Region: vertebral / hip / wrist / other.
- Other: ……..

● **Neuro-psychiatric disorder(s):**

- No significant changes / Disorder is over / Improvement / Worsening / No data

- Any new significant neuro-psychiatric disorder(s) **yes / no / no data**
└ If yes: - When was diagnosed: ……
- Type:
Depression / Anxiety disorder / Chronic pain syndrome /
Cognitive problems / Other (please describe): ……

- Controlled by treatment: yes / no / not applicable / no data

● **Other disorder(s):**

- No significant changes / Disorder is over / Improvement / Worsening / No data

- Any new significant other disorder(s): **yes / no / no data**
└ If yes: - What disorder: ……..
- Since when: ……..

- Controlled by treatment: yes / no / not applicable / no data

● **Non-pituitary surgery:**

- Recent (non-pituitary) surgery: yes / no / no data

└ If yes: - What was: ……
- When: ……..

● **Pregnancy:**

- Any new pregnancy: yes / no / no data

└ If yes: - When: ……..
- Delivery: yes / no

● **Alcohol consumption:**

- No significant changes / Stopped consuming alcohol / Improvement / Worsening / No data

- Any significant new alcohol consumption: yes / no / no data

└ If yes: - Frequency: not available / occasionally / monthly / weekly / daily.
- Amount (per occasion): …….
- For how many years? …….

● **Smoking habits:**

- No significant changes / stopped smoking / Improvement / Worsening / No data

Any significant new smoking habits: **yes / no / no data**

└ If yes: - Amount (cigarettes/day): …….
- Since when: ……..

● **Drug abuse**:

- No significant changes / stopped smoking / Improvement / Worsening / No data

Any new significant drug abuse: yes / no / no data

└ If yes: - Type of drug: ……..
- Amount: ……..
- For how many years and/or month if available: …….

4. Any significant changes in family history yes / no / no data

If yes:

- **Tumorous disease in family history: yes / no / not available**

  - **Pituitary tumor**: **yes / no**
    - If yes: relationship to patient:
      - mother / father / maternal grandfather / maternal grandmother / paternal grandmother / paternal grandfather / sister / brother / daughter / son / other (please describe): …..

  - **Brain tumor**: **yes / no**
    - If yes: relationship to patient:
      - mother / father / maternal grandfather / maternal grandmother / paternal grandmother / paternal grandfather / sister / brother / daughter / son / other (please describe): ……

  - **Thyroid gland tumor: yes / no**
    - If yes: relationship to patient:
      - mother / father / maternal grandfather / maternal grandmother / paternal grandmother / paternal grandfather / sister / brother / daughter / son / other (please describe): ……

  - **Gastrointestinal tumor: yes / no**
    - If yes: relationship to patient:
      - mother / father / maternal grandfather / maternal grandmother / paternal grandmother / paternal grandfather / sister / brother / daughter / son / other (please describe): ……

  - **Hematological tumor: yes / no**
    - If yes: relationship to patient:
      - mother / father / maternal grandfather / maternal grandmother / paternal grandmother / paternal grandfather / sister / brother / daughter / son / other (please describe): ……

  - **Skin/ soft tissue tumor: yes / no**
    - If yes: relationship to patient:
      - mother / father / maternal grandfather / maternal grandmother / paternal grandmother / paternal grandfather / sister / brother / daughter / son / other (please describe): ……

  - **Urological tumor: yes / no**
    - If yes: relationship to patient:
      - mother / father / maternal grandfather / maternal grandmother / paternal grandmother / paternal grandfather / sister / brother / daughter / son / other (please describe): ……

  - **Gynecological tumor: yes / no**
    - If yes: relationship to patient:
      - mother / father / maternal grandfather / maternal grandmother / paternal grandmother / paternal grandfather / sister / brother / daughter / son / other (please describe): ……

- **Breast cancer:** **yes / no**
  - If yes: relationship to patient:
    - mother / father / maternal grandfather / maternal grandmother / paternal grandmother / paternal grandfather / sister / brother / daughter / son / other (please describe): ……

- **Other**: ……
  - Relationship to patient*:
    - mother / father / maternal grandfather / maternal grandmother / paternal grandmother / paternal grandfather / sister / brother / daughter / son / other (please describe): ……

● **New diseases:** **yes / no / no data**
if yes: please list/describe them: ……
……

5. Any significant changes in treatment of acromegaly

Any change in the therapy: yes / no / no data
└ If yes:

● **Any new surgical therapy:** **yes / no**
└ If yes:

➔ **FORM C - Surgical therapy**

● **Any significant changes in the medical therapy**: **yes / no**
└ If yes:

➔ **FORM D - Medical therapy**

● **Any new radiotherapy:** **yes / no**
└ If yes:

➔ **FORM E - Radiotherapy**

6. Any significant changes in relevant, not acromegaly medications taken regularly: yes / no / no data

If yes:
● Medication: ……

● Active substance: ……..

● Dose: ……. g ***or*** ……. mg ***or*** ……. IU

● How many times per day (e.g. 3): …….

● Method of administration: oral / nasal / transdermal / subcutaneous / intramuscular / intravenous/ other.

- other: ……..

● Other notes: ……

……

……

7. Outcome

● Not available for endocrine care/ Regular follow-up / Death * / No data.

* Date of death: …. . .. .