Transversal Working Group on Transition of Care

Endo-ERN General Assembly 2026

Andrea Isidori (AOU Policlinico Umberto I, Rome, Italy)
Ulla Döhnert (Universitätsklinikum Schleswig-Holstein, Lübeck, Germany)
Chairs

Funded by
the European Union

Delivering on 2025 Commitments

- ✓ **Endo-ERN ‘Transition of Care’ Survey**
  - Data analysis completed
  - Manuscript published
- ✓ **Minimal Standards for Transition of Care**
  - Core standards identified
  - Translated into structured checklists for RECs
- ✓ **Collaboration with ESPE/ESE Working Groups**
  - Active exchange established
  - Alignment on transition strategies
- ✓ **ERN Cross-Network Engagement**
  - Interaction with Overarching ERN Working Group
  - Participation in joint workshops

All key 2025 objectives have been successfully met!

ToC Working Group

Members

Endo-ERN 'Transition of Care' Working Group

N	MTG / Role	Representative	Ped/Adu	E-mail (transitionwg@endo-ern.eu)
1	**Chair**	**Andrea Isidori**	**Adu**	andrea.isidori@uniroma1.it
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Key Milestones

Cooperation with ESPE/ESE working group
& overarching ERN working group on ToC

Formation

Work in progress…

Endo-ERN GA
Milano
23-24/04/2024

Online
kick-off meeting
24/09/2024

TALENT Meeting
Rome
12-14/02/2025

Endo-ERN GA
Copenhagen
9-10/05/2025

Checklist development
& exploratory survey
Nov. 24 – Feb. 26

TALENT Meeting
Rome
11-13/02/2026

Aims

1. **To map current practices** in Endo-ERN centres to facilitate transition from paediatric to adult care
2. **To collect and review current/ongoing activities** in Endo-ERN aimed at improving transition from paediatric to adult care
3. **To identify best practice standards** for transition of care for adolescents/young adults with rare endocrine conditions
4. **To create and promote key resources** to facilitate best practice in transition of care within our network member healthcare providers

1. **To map current practices** in Endo-ERN centres to facilitate transition from paediatric to adult care
2. **To collect and review current/ongoing activities** in Endo-ERN aimed at improving transition from paediatric to adult care

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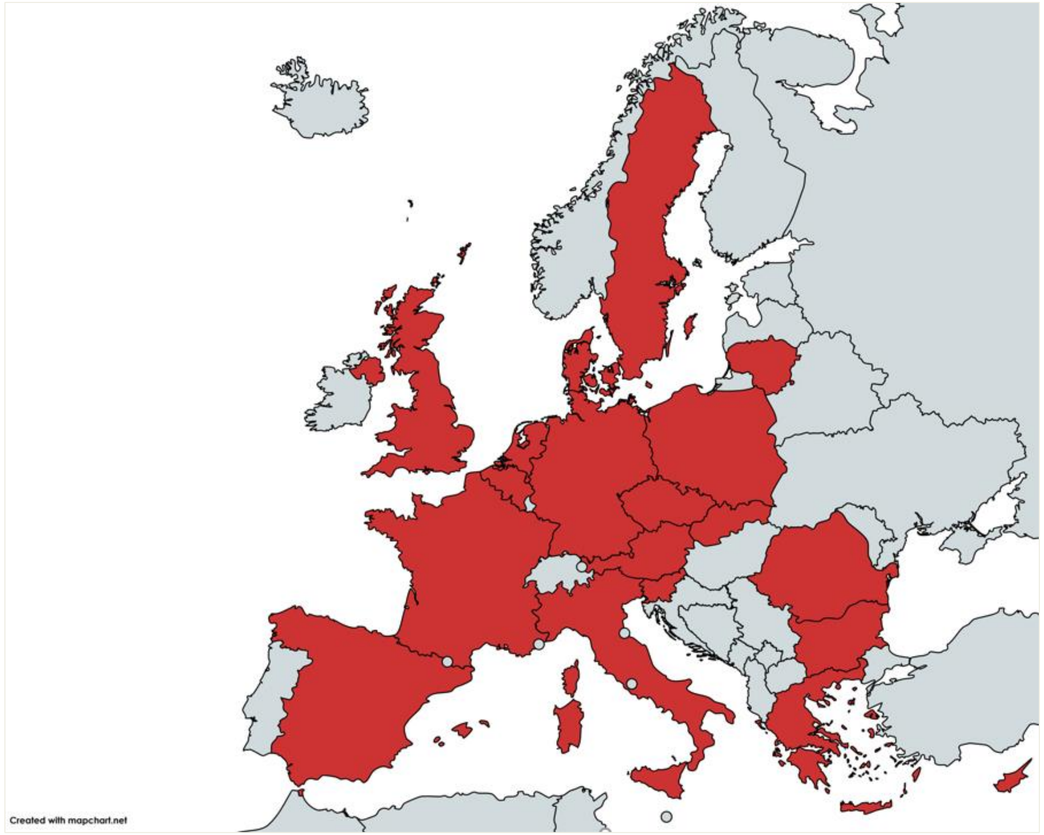
Endo-ERN ‘Transition of Care’ Survey

- January – March 2025
- **112 responses** from
- 19 European countries
- **77 Total Centres**
- **63 ERN Centres** (81.8%)



Endocrine CONNECTIONS

Society for Endocrinology

European Society of Endocrinology

European Reference Network

Endo-ERN

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RESEARCH

Mapping transition of care for rare endocrine conditions: findings from a cross-sectional survey by the Endo-ERN ToC Working Group*

Francesco Carlomagno[1,2,†], Matteo Spaziani[1,2,†], Charlotte MW Gaasterland[3], Svetlana Lajic[4], Nicole Reisch[5], Uta Neumann[6], Corinna Grasemann[7], Eva Kassi[8,9], Graziamaria Ubertini[10], Felix Reschke[11], Pietro Maffei[12], Annemarie Verrijn Stuart[13], Susan M O'Connell[14], Claudia Giavoli[15,16], Danilo Fintini[10], Evangelia Charmandari[17], Nienke R Biermasz[18], Violeta Iotova[19], Hedi L Claahsen-van der Grinten[20], Kirstine Stochholm[21], Dana Craiu[22], Andreea Ioana Badea[22], Aglaia Kyrilli[23], Enora Le Roux[24], Sebastian Neggers[25], Ulla Döhnert[26] and Andrea M Isidori[1,2]

3. **To identify best practice standards** for transition of care for adolescents/young adults with rare endocrine conditions
4. **To create and promote key resources** to facilitate best practice in transition of care within our network member healthcare providers

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- Non-negotiable essentials – key elements not to be missed during transition
- Information transfer – what the adult endocrinologist needs to know
- Crucial monitoring
- Adolescent-specific considerations
- Monitoring frequency
- Success measures/Outcome quality indicators
- Open issues

3. **To identify best practice standards** for transition of care for adolescents/young adults with rare endocrine conditions
4. **To create and promote key resources** to facilitate best practice in transition of care within our network member healthcare providers

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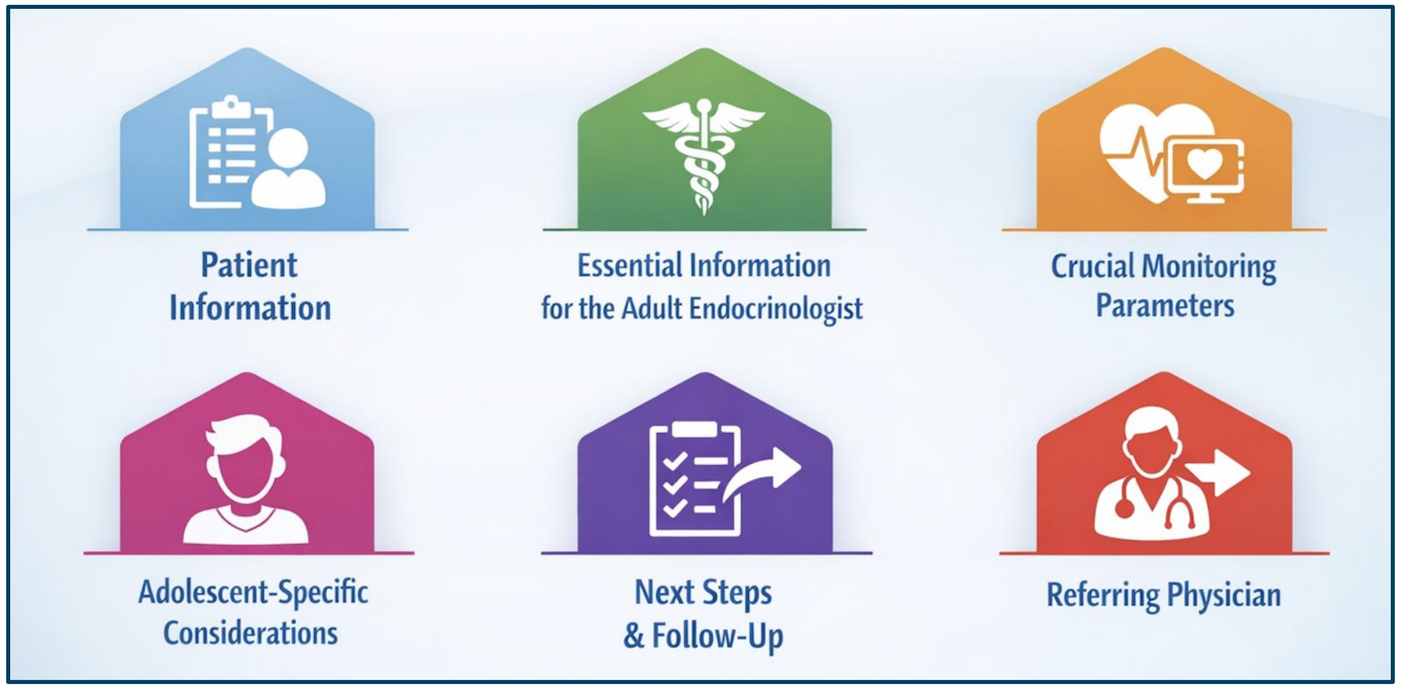
Development of 'condition-specific checklists' for transition of care

MTG-1	CAH
MTG-2	X-linked hypophosphatasia
MTG-3	Monogenic Diabetes
MTG-4	MEN 1
MTG-5	Prader-Willi syndrome
MTG-6	AVP deficiency
MTG-7	cHH - Turner syndrome
MTG-8	Congenital hypothyroidism

Harmonisation framework across MTGs

To ensure consistency, all checklists were developed using a shared **6-domain structure**



Checklist for Transitioning Patients with Congenital Adrenal Hyperplasia (CAH)

(To be completed by the referring paediatric endocrinologist and shared with the receiving adult endocrinologist)

1. Patient Information

- **Name & Surname:** _____
- **Date of Birth:** ___ / ___ / _____ **Gender:** ☐ Male ☐ Female

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2. Essential Information for the Adult Endocrinologist

- **Diagnosis of CAH confirmed at age:** _____, ☐ Prenatal (genetic or neonatal screening)
- **Prenatal dexamethasone treatment:** ☐ Yes ☐ No
- **Salt wasting at birth:** ☐ Yes ☐ No
- **ACTH stimulation testing:** ☐ Yes (☐ Attached) ☐ No
- **Genetic testing performed:** ☐ Yes (☐ Attached) ☐ No
  - If yes, result: _____
- **External masculinization score (EMS) at birth:** _____
- **Current Prader stage (in females):** _____
- **Genital surgery (in females):** ☐ Yes (☐ Attached) ☐ No
  - If yes, date(s): ___ / ___ / _____ -- ___ / ___ / _____ -- ___ / ___ / _____
  - Type of surgery:_____
- **Perinatal history:** _____
  _____
- **Growth**
  - Growth chart: ☐ Yes, attached ☐ No
  - Completed linear growth (<2 cm/year): ☐ Yes ☐ No
- **Age at pubertal onset:** _____, **menarche:** _____ **regular menses:** ☐ Yes ☐ No
- **Pubertal stage (according to Tanner):** _____
- **Glucocorticoid replacement therapy**
  - Current formulation: _____
  - Dose & route of administration: _____
- **Mineralocorticoid replacement therapy**
  - Current formulation: _____

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MTG-1

CAH

Checklist for Transitioning Patients with X-linked hypophosphatemia (XLH)
(To be completed by the referring paediatric endocrinologist/nephrologist/orthopaedic surgeon and shared with the receiving adult endocrinologist/nephrologist/orthopaedic surgeon)

---

1. Patient Information

☐ **Name & Surname:** _____

☐ **Date of Birth:** ___ / ___ / _____

☐ **Gender:** ☐ Male ☐ Female

☐ **Age at confirmation of XLH diagnosis:** _____

☐ **Genetic analysis performed:** ☐ Yes ☐ No

- If yes, result: _____

☐ **Patient contact**: _____

☐ **Family / caregiver contact**: _____

☐ **Current / future living situation:** _____

☐ **Legal / administrative aspects defined** *(e.g., caregiver responsibility, decision-making authority, communication preferences)*: _____

☐ **Current medication**

---

2. Essential Information for the Adult Endocrinologist

☐ **Current and previous XLH-specific treatment**

- **Conventional**
  ☐ Yes ☐ No
  If yes:
  - Age at initiation: _____
  - Regimen(s): _____
  - Dosage: _____
- **Burosumab**
  ☐ Yes ☐ No
  If yes:
  - Age at initiation: _____
  - Dosage: _____
- Other medications (e.g., pain medication, antihypertensive treatment, etc.)
  ☐ Yes ☐ No
  If yes, specify:

☐ **Medication regimen provided**: ☐ Yes ☐ No

☐ **XLH-related complications**

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MTG-2

XLH

Checklist for transitioning patients with Monogenic Diabetes / MODY

(To be completed by the referring paediatric diabetologist and shared with the receiving adult diabetologist)

1. Patient Information

- Name & Surname: _____
- Date of Birth: ___ / ___ / _____ Gender: ☐ Male ☐ Female

---

2. Essential Information for the Adult Diabetologist

- Diagnosis of monogenic diabetes / MODY confirmed at age: _____
- Age at diabetes diagnosis: _____
- Genetic testing performed: ☐ Yes (☐ Attached) ☐ No
  - o If yes, gene / MODY subtype: _____
  - o Variant classification: _____
- Family history of diabetes: ☐ Yes ☐ No
  - o If yes, specify: _____
- Family genetic testing completed / offered: ☐ Yes ☐ No
  - o If yes, specify: _____
- Syndromic / extrapancreatic features assessed: ☐ Yes ☐ No
  - o If yes, specify: _____
- Renal involvement assessed: ☐ Yes ☐ No ☐ Not applicable
  - o If yes, specify: _____
- Current therapy: _____

_____

- Use of diabetes technology: ☐ Yes ☐ No
  - o If yes: ☐ CGM ☐ Insulin pump ☐ Hybrid closed loop ☐ Other: _____
- Gene-specific recommendations for adult care: _____

_____

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3. Crucial Monitoring Parameters

- HbA1c trajectory available, last evaluation date: ___ / ___ / _____ Result: _____

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MTG-3

Monogenic Diabetes

Checklist for Transitioning Patients with Multiple Endocrine Neoplasia Type 1 (MEN1)

(To be completed by the referring paediatric endocrinologist and shared with the receiving adult endocrinologist)

---

1. Patient Information

☐ **Name & Surname**: _____

☐ **Date of Birth**: ___ / ___ / _____

☐ **Gender:** ☐ Male ☐ Female

☐ **Hospital ID Number** (if applicable): _____

☐ **Social security number** (if applicable): _____

☐ **Patient contact**: _____

☐ **Family / caregiver contact**: _____

☐ **Current / future living situation**: _____

☐ **Legal / administrative aspects defined** (*e.g., caregiver responsibility, decision-making authority, communication preferences*): _____

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2. Essential Information for the Adult Endocrinologist

☐ **Last clinical evaluation date**: ___ / ___ / _____

☐ **Anthropometric data**
- Height: _____
- Weight: _____

☐ **Non-MEN1 associated conditions**: ☐ Yes ☐ No
→ If yes, specify: _____

☐ **Growth and development**
- Growth chart: ☐ Yes, attached ☐ No

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MTG-4

MEN 1

Checklist for Transitioning Patients with Prader Willi Syndrome (PWS)

(To be completed by the referring paediatric endocrinologist and shared with the receiving adult endocrinologist)

---

1. Patient Information

☐ **Name & Surname**: _____

☐ **Date of Birth**: ___ / ___ / _____

☐ **Gender:** ☐ Male ☐ Female

☐ **Genetic diagnosis (type of PWS)**: _____

☐ **Patient contact**: _____

☐ **Family/caregiver contact**: _____

☐ **Current/future living situation**: _____

☐ **Legal/administrative aspects defined** *(e.g., caregiver responsibility, decision-making authority, communication preferences)*: _____

☐ **Residential facility contact**: _____

☐ **District nurse / home care contact**: _____

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2. Essential Information for the Adult Endocrinologist

☐ **Birth**:

- Weight (Kg/SD): _____
- Hypotonia: ☐ Yes ☐ No
- Nasal Tube Nutrition: ☐ Yes ☐ No
- Cryptorchidism: ☐ Yes ☐ No
- Age of surgery for cryptorchidism: _____

☐ **Age of confirmation of PWS diagnosis**: _____

☐ **Registered in PWS registry (if applicable):** ☐ Yes ☐ No

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MTG-5

PWS

MTG-6

AVP deficiency

cHH

Checklist for Transitioning Patients with Congenital Hypogonadotropic Hypogonadism (cHH)
(To be completed by the referring paediatric endocrinologist and shared with the receiving adult endocrinologist)

1 Patient Information

- **Name & Surname:** _____
- **Date of Birth:** ___ / ___ / _____ **Gender:** ☐ Male ☐ Female

2 Essential Information for the Adult Endocrinologist

- **Diagnosis of cHH confirmed at age:** _____
- **GnRH (or dynamic) testing:** ☐ Yes (☐ Attached) ☐ No
- **Presence of cryptorchidism:** ☐ Yes ☐ No
  - If yes, side and treatment: _____
- **Olfactory function assessment performed:** ☐ Yes (☐ Attached) ☐ No
  - If yes, anosmia / hyposmia / normal: _____
- **Genetic analysis performed:** ☐ Yes (☐ Attached) ☐ No
  - If yes, result: _____
- **MRI of the CNS performed:** ☐ Yes (☐ Attached) ☐ No
  - If yes, result: _____
- **Bone health assessed (DXA, vertebral morphometry):** ☐ Yes (☐ A
  - If yes, result: _____
- **Any psychological / psychosocial issues:** ☐ Yes (☐ Psychological r
  - If yes, specify: _____
- **Pubertal induction therapy**
  - Age at initiation: _____
  - Regimen: _____
  - Duration: _____
- **Growth**
  - Growth chart: ☐ Yes, attached ☐ No
  - Completed linear growth (<2 cm/year): ☐ Yes ☐ No
- **Pubertal stage (according to Tanner):** _____
- **Testosterone (T) / Estrogen-Progestin (EP) replacement therapy**
  - Current formulation: _____

Checklist for transitioning patients with Turner Syndrome (TS)
(To be completed by the referring paediatric endocrinologist and shared with the receiving adult endocrinologist)

1. Patient Information

- Name & Surname: _____
- Date of Birth: ___ / ___ / _____

2. Essential information for Adult Endocrinologist

- Diagnosis of TS confirmed at age: _____
- Gender / karyotype: (☐ Attached) _____
- Mosaicism: ☐ Yes (on blood or other tissues: _____) ☐ No
- Gonadectomy performed (in case of Y chromosome material): ☐ Yes ☐ No
  - If no, specify: _____
  - rhGH therapy: ☐ Yes ☐ No, age at initiation / discontinuation _____
- Growth chart: ☐ Yes, attached ☐ No
- Completed linear growth (<2 cm/year): ☐ Yes ☐ No
- Pubertal induction therapy: ☐ Yes ☐ No
  - Age at initiation: _____
  - Regimen and duration: _____
- Spontaneous menarche: ☐ Yes ☐ No
- Current estrogen-progestin replacement therapy: ☐ Yes ☐ No
  - Current formulation: _____
  - Dose & route: _____
  - Regular bleeding pattern: ☐ Yes ☐ No ☐ Not applicable
- Main comorbidities: _____
- Current medications: _____
- Fertility and reproductive goals discussed with patient: ☐ Yes ☐ No
- Fertility preservation considered / performed: ☐ Yes (☐ Attached) ☐ No
  - If yes, specify: _____

3. Crucial Monitoring parameters

TS

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MTG-7

cHH - Turner syndrome

Checklist for Transitioning Patients with Congenital Hypothyroidism (CH)

(To be completed by the referring paediatric endocrinologist and shared with the receiving adult endocrinologist)

---

1. Patient Information

- **Name & Surname:** _____
- **Date of Birth:** ___ / ___ / _____ **Gender:** ☐ Male ☐ Female
- **NHS / Hospital ID Number (if applicable):** _____

---

2. Essential Clinical Information for the Adult Endocrinologist

- **Diagnosis of Congenital Hypothyroidism confirmed at age:** _____
- **Newborn screening result available:** ☐ Yes (☐ Attached) ☐ No
- **Etiology identified:**
  - ☐ Thyroid dysgenesis
  - ☐ Dyshormonogenesis
  - ☐ Central hypothyroidism
  - ☐ Unknown
  - ☐ Genetic diagnosis: _____ (☐ Attached)
- **Imaging (e.g., thyroid ultrasound / scintigraphy):** ☐ Yes (☐ Attached) ☐ No
  - → If yes, result:

_____

- **Thyroid Function Tests** (TSH, Free T4, Free T3):
  - → Most recent values and dates:
    - TSH: _____ Date: ___ / ___ / _____
    - FT4: _____ Date: ___ / ___ / _____
    - FT3: _____ Date: ___ / ___ / _____
  - ☐ Lab reports attached
- **Treatment history:**
  - Age at initiation of levothyroxine: _____
  - Initial dose: _____ mcg/day
  - Current dose: _____ mcg/day
  - Adherence issues noted: ☐ Yes ☐ No
  - → If yes, details: _____
- **Growth and development:**
  - Growth chart: ☐ Yes, attached ☐ No
  - Neurocognitive development normal: ☐ Yes ☐ No
  - → If no, specify: _____
- **Associated conditions (e.g., hearing impairment, other pituitary deficiencies):**
  - ☐ Yes ☐ No → Specify:

_____

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MTG-8

Congenital hypothyroidism

8-TALENT:

Transition Adolescence and young aduLts -Endocrine diseases managemenT

An *Endo-European Reference Network* event

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8th-TALENT Conference Meeting

Endo-ERN TALENT TRANSITION OF CARE WORKING GROUP

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- Rare adrenal diseases
- Calcium and phosphate disorders
- Rare forms of diabetes
- Genetic endocrine tumour syndromes
- Growth and genetic obesity syndromes
- Rare thyroid diseases
- Hypothalamic-pituitary conditions
- Sexual development disorders

8th-TALENT Conference Meeting Agenda

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TALENT for ADRENAL DISEASES – Endo-ERN MTG1 Symposium

Moderators: C. Scaroni; F. Pecori-Giraldi

14:00-14:20 **LECTURE 1 :** Cushing's syndrome in transition to adulthood: comparative management between adolescents and adults - **Antoine Tabarin**, *Hopital Haut-Lévêque C.H.U de Bordeaux, Pessac, France*

14:20-14:40 **LECTURE 2 :** Impact of novel therapeutic concepts on transitional care pathways - **Nicole Reisch**, *Ludwig-Maximilian-University Munich, Munchen, Germany*

14:40-15:00 **LECTURE 3 :** Autoimmune adrenal insufficiency in youth: from isolated Addison's to polyglandular syndromes - **Rosario Pivonello**, *University of Naples Federico II, Naples, Italy*

15:00-15:20 Discussion

TALENT for DISORDERS OF CALCIUM & PHOSPHATE HOMEOSTASIS – Endo-ERN MTG2 Symposium

Moderators: E. Kassi; N. Napoli

15:20-15:40 **LECTURE 4 :** Translating new clinical recommendations into care: Burosumab and skeletal outcomes in young adults with XLH - **Francesco Emma**, *IRCCS Bambino Gesù Children's Hospital, Rome, Italy*

15:40-16:00 **LECTURE 5 :** Bone health in functional hypothalamic amenorrhoea: challenges and strategies during transition to adulthood - **Giovanna Mantovani**, *Department of Clinical Sciences and Community Health, University of Milan, Milan, Italy*

16:00-16:20 **LECTURE 6 :** Novel agents in the management of hypoparathyroidism and related disorders: focus on transition and young adults - **Andrea Palermo**, *Unit of Endocrinology and Diabetes, Campus Biomedico University, Rome, Italy*

16:20-16:40 Discussion

16:40-17:00 Coffee break

TALENT for GENETIC DISORDERS OF GLUCOSE & INSULIN HOMEOSTASIS – Endo-ERN MTG3 Symposium

Moderators: S. Cannavò; T. Filardi

17:00-17:20 **LECTURE 7 :** MODY and other non-typical forms of diabetes in young adults: when the diagnosis comes late - **Pietro Maffei**, *University of Padua, Padua, Italy*

17:20-17:40 **LECTURE 8 :** Obesity in type 1 diabetes: drivers and challenges for a novel immunometabolic issue - **Ernesto Maddaloni**, *Sapienza University of Rome, Italy*

17:40-18:00 Discussion

Conclusions of the day's work

TALENT for GENETIC ENDOCRINE TUMOUR SYNDROMES – Endo-ERN MTG4 Symposium

Moderators: A.B. Grossman; C. Giavoli

13:00-13:20 **LECTURE 9 :** MEN1 in young adults: new guidelines for tumour screening and transition care - **Franz Sesti**, *Sapienza University of Rome, Italy*

13:20-13:40 **LECTURE 10 :** Integrating RET-targeted therapy advances into the transitional management of MEN2A and MEN2B syndromes - **Cosimo Durante**, *Sapienza University of Rome, Italy*

13:40-14:00 **LECTURE 11 :** Von Hippel-Lindau syndrome and developments in other endocrine tumor syndromes - **Annemarie Verrijn-Stuart**, *Wilhelmina Kinderziekenhuis, Utrecht, Netherlands*

14:00-14:20 Discussion

TALENT for GROWTH & GENETIC OBESITY SYNDROMES – Endo-ERN MTG5 Symposium

Moderators: P. Maffei; S. Migliaccio

14:20-14:40 **LECTURE 12 :** Evolving treatments for obesity in adolescents and young adults: from novel agonists to holistic management - **Susan O' Connell**, *Children's Health Ireland, Dublin, Ireland*

14:40-15:00 **LECTURE 13 :** Bardet-Biedl syndrome: from clinical challenges to targeted treatments in youth and young adults - **Giovanni Ceccarini**, *Pisa University Hospital, Pisa, Italy*

15:00-15:20 **LECTURE 14 :** Navigating the challenges of Prader-Willi syndrome: from hyperphagia to hormonal therapies in transition age - **Danilo Fintini**, *IRCCS Bambino Gesù Children's Hospital, Rome, Italy*

15:20-15:40 Discussion

15:40-16:10 Coffee break

TALENT for HYPOTHALAMIC AND PITUITARY CONDITIONS– Endo-ERN MTG6 Symposium

Moderators: E. Charmandari; V. Iotova; F. Pecori-Giraldi

16:10-16:30 **LECTURE 15 :** Therapeutic innovations in growth disorders: from daily and long-acting GH to IGF-1 replacement - **Alberto Pereira**, *Amsterdam UMC Meibergdreef 9, Netherlands*

16:30-16:50 **LECTURE 16 :** Transitioning with prolactinomas: clinical course and management strategies - **Nienke Biermasz**, *Leids Universitair Medisch Centrum, Leiden, Netherlands*

16:50-17:10 **LECTURE 17 :** Oxytocin and adolescence: neuroendocrine dynamics and clinical implications - **Mirjam Christ-Crain**, *Universitätsspital Basel, Basel, Switzerland*

17:10-17:30 Discussion

17:30-17:50 **LECTURE 18 :** (recovery lecture **Endo-ERN MTG3 Symposium**). Lessons from the field: barriers and breakthroughs in transitioning youth with rare diabetes - **Felix Reschke**, *Diabetes-Zentrum für Kinder und Jugendliche, Hannover, Germany*

Conclusions of the day's work

TALENT for SEX DEVELOPMENT & MATURATION– Endo-ERN MTG7 Symposium

Moderators: M. Cappa; U. Döhnert

09:00-09:20 **LECTURE 19 :** DSD: diagnostic complexity, therapeutic variability and the search for shared protocols - **Olaf Hiort**, *Universitätsklinikum Schleswig-Holstein, Lubeck, Germany*

09:20-09:40 **LECTURE 20 :** PCOS and pubertal disorders: implications for fertility across the lifespan - **Krystallenia Alexandraki**, *National and Kapodistrian University of Athens, Greece*

09:40-10:00 **LECTURE 21 :** "EAA Educational Course" from gonadotropins to sex steroids: puberty induction and transitional care in male hypogonadism - **Hedi Claahsen**, *Radboud University Medical Center, Nijmegen, Netherlands*

10:00-10:20 Discussion

TALENT for THYROID DISEASES – Endo-ERN MTG8 Symposium

Moderators: E. Giannetta; C. Virili

10:20-10:40 **LECTURE 22 :** Graves' disease in transition age: rethinking antithyroid drug strategies and dosing approaches - **Aglaia Kyrilli**, *Hôpital Erasme, Brussels, Belgium*

10:40-11:00 **LECTURE 23 :** Differentiated thyroid cancer in young adults: do we need a molecular-based follow-up? **Marco Centanni**, *Sapienza University of Rome, Italy*

11:00-11:20 **LECTURE 24 :** Levothyroxine adherence in young adults: why are we still getting it wrong? - **Grazia Maria Ubertini**, *IRCCS Bambino Gesù Children's Hospital, Rome, Italy*

8th-TALENT Conference Meeting
Roundtable

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"VOICES IN TRANSITION": ROUNDTABLE BETWEEN PHYSICIANS AND PATIENT ASSOCIATIONS

Moderators: M.L. Jaffrain-Rea; M. Spaziani; F. Carlomagno

12:00-14:00 **Panel Discussion**

MTG 1: Discussant: **Rosa Maria Paragliola**
Patient Association Representative: Associazione Italiana Pazienti Addison - AIPAd (*Simone Genovese, Roma*)

MTG 2: Discussant: **Stefano Frara**
Patient Association Representative: Associazione Italiana dei Pazienti con Disordini Rari del Metabolismo del Fosfato - AIFOSF (*Nicoletta Schio, Vicenza*)

MTG 3: Discussant: **Tiziana Filardi**
Patient Association Representative: Federdiabete Lazio APS (*Lina Delle Monache, Roma*)

MTG 4: Discussant: **Franz Sesti**
Patient Association Representative: Associazione Italiana Tumori Neuroendocrini - AINET (*Giovanni Guglielmi, Roma*)

MTG 5: Discussant: **Marianna Minnetti**
Patient Association Representative: Associazione Sindrome di Bardet-Biedl Italia APS - ASBBI (*Susanna Genova, Palermo; Arianna Foti, Monza*)

MTG 6: Discussant: **Antonio Bianchi**
Patient Association Representative: Associazione Italiana Displasia Setto Ottica e altri Disordini Neuroendocrini - SOD ITALIA APS (*Diana Vitali, Roma*)

MTG 7: Discussant: **Marta Tenuta**
Patient Association Representative: Nascere Klinefelter APS (*Pamela Pedretti, Firenze*)

MTG 8: Discussant: **Carlotta Pozza**
Patient Association Representative: Comitato Associazioni Pazienti Endocrini & La Lumaca ODV (*Anna Maria Biancifiori, Perugia*)

ESPE-ESE Transition of Care Working Group

Now published:

European Society for Paediatric Endocrinology and European Society of Endocrinology Joint Clinical Practice Guidance for Healthcare Transition from Paediatric to Adult Endocrine Care

Horm Res Paediatr (2026), doi: 10.1159/000550744

Future directions:

- Supplementary condition-specific guidance
- Definition of transition success
- Feasibility of research and research questions

Overarching ERN Transition of Care Working Group

- Regular online meetings
- Workshop in Ghent

European Reference Network

Endo-ERN

84 Participants

Adult care physicians, paediatricians, young patients, patient advocates, psychologists, social workers, nurses, transition specialists, policy advisors, project managers, researchers

22 European Reference Networks

16 European countries

Bulgaria, Cyprus, Republic of Moldova, Poland, Portugal

Austria, Belgium, Denmark, France, Germany, Ireland, Italy, Netherlands, Norway, Spain, United Kingdom

Preparatory Work

- Healthcare Provider Survey (n=481)
- Interviews with young people (n=15)
- Patient survey (n=114)

Identified (sub)themes

Communication: open communication/ between HCPs/ between HCP and AYA

Organization: Care environment/ continuity of care/ components of transfer journey

Education: Trainings HCPs/ Training AYAs/ Peer support

Psychosocial wellbeing: Navigating growing up/ mental health/ social support and autonomy

Results: Fundamental principles of transition in rare conditions

- Establish contact between paediatric and adult care services
- Provide contact details and discuss communication strategies
- Inform about future care
- Use transfer documents

  → Providing information

- Offer psychosocial support
- Offer peer contact

  → Providing support

- Integrate transition into education and training for HCPs

Overarching ERN Transition of Care Working Group

Future directions:

- Youth panel review of workshop results and publication
- Cross-ERN systematic review of existing surveys on the mapping of transition processes
- Common document on sexual health and fertility in young people with rare conditions and disabilities

Next steps…

- ✓ Development of additional condition-specific checklists and pilot implementation in selected Endo-ERN centres for real-world evaluation
- ✓ Collection of user feedback (HCPs and patients)
- ✓ Contribution to the development of specific guidelines for the transition from paediatric to adult care
- ✓ Scientific commentary to support uptake of disease-specific transition checklists
- ✓ **Exploration of strategies to assess transition outcomes**
  - Validation by receiving adult endocrinologist?
  - Tracking of transition pathways (registry-based)?
  - Potential Endo-ERN transition certification?
  - Other options?

ToC Working Group

→ Dedicated upcoming meetings to define feasible approaches

Questions? Questions!

Photo: TALENT Meeting in Rome