Endocrine transition of care from pediatric to adult medicine in adolescents and young adult survivors of childhood brain tumor. Experience at Hôpital Universitaire Necker – Enfants Malades and Hôpital Universitaire La Pitié-Salpêtrière – a follow-up study of the 2010-2015 cohort.

González Briceño L[1,2], Samara-Boustani D[1,3], Beltrand J[1,3,4], Grill J[5], Puget S[6], Dufour C[5], Sainte-Rose C[6], Alapetite C[7], Pinto G[1,3], Touraine Ph[3,15,16]Valteau-Couanet D[5], Kariyawasam D[1,3], Aerts I[8], Beccaria K[6], Bourgeois M[6], Roujeau T[9], Blauwblomme T[6], DiRocco F[10], Thalassinos C[1,3], Zerah M[6], Pauwels C[1,3], Brugieres L[5], James S[6], Doz F[4,8,11], Busiah K[12], Simon A[13], Bourdeaut F[8,11], Bolle S[5], Fresneau B[5], Guerrini-Rousseau L[5], Michon J[8], Orbach D[8,11,14,], Polak M[1,3,4]

1. AP-HP, Hôpital Universitaire Necker Enfants Malades, Endocrinologie, gynécologie et diabétologie pédiatrique, Institut IMAGINE (affiliate), Paris, France. 2. ESPE Fellowship. 3. Centre de référence des maladies endocriniennes rares de la croissance (CRMERC), Paris, France. 4. Université Paris Descartes, Paris, France. 5. Institut Gustave Roussy, Department of Pediatrics, Villejuif, France. 6. AP-HP, Hôpital Universitaire Necker Enfants Malades, Service Neurochirurgie, Paris, France. 7. Institut Curie, Radiotherapy Centre, Orsay, France. 8. Institut Curie, Pediatric Department, Paris, France. 9. CHU Montpellier, Hôpital Gui de Chauliac, Unité de Neurochirurgie Pédiatrique, Montpellier, France. 10. CHU Lyon-Bron, Service de Neurochirurgie, Bron, France. 11. SIREDO Oncology Center (Care, Innovation and Research for Children, Adolescents and Young Adults with Cancer). 12. CHUV, Pediatric Endocrinology Department, Lausanne, Suisse. 13. Hôpital André Mignot, Le Chesnay, Endocrinologie Pédiatrique, Le Chesnay, France. 14. PSL Research University, Paris, France. 15. AP-HP, Hôpital Universitaire La Pitié-Salpêtrière, Service Endocrinologie et médecine de la reproduction, Paris, France. 16. Sorbonne Université Médecine, Paris, France.

Background: Childhood brain tumour survivors are at risk of developing endocrine secondary effects throughout lifetime. Transition between childhood and adult care is a critical moment during which patients may stop medical visits and treatments.

Objective: To describe endocrine care transition in our cohort of patients with primary brain tumors followed from 2010-2015, who are ≥18 years old by December 31st 2017.

Methods: Retrospective and prospective observational study, data collection from medical records of patients seen at least once between 2010-2015. Patients with pituitary adenomas, untreated fortuitously diagnosed gliomas (NF1 context), who died before transition or with insufficient data were excluded.

Results: 74 patients were included, 34 females.
- Median age at diagnosis: 10.7 years (1.5-15.1)
- Median age at last visit: 21.3 years (17.1-29.9)
- Delay between diagnosis and first endocrine visit: 1.3 years (0-5.9)
- Median follow-up (last visit): 9.5 years (1.5-25.5)

Main tumour subtypes: medulloblastoma (37.8%), craniopharyngioma (35.1%), glioma (13.5%).

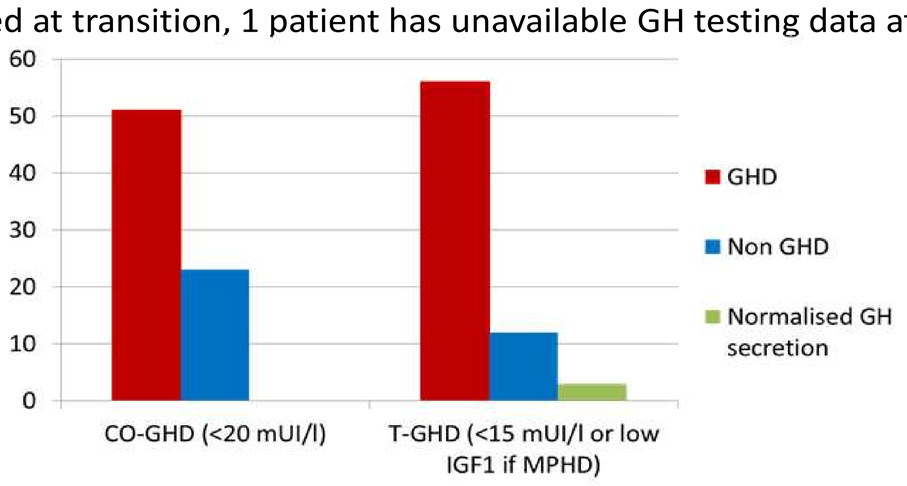
Patients were divided into 2 groups: suprasellar (SS: 52.7%) and non-suprasellar (NSS: 47.3%).

TRANSITION:
- 59/74 (79.7%) have started transition
- 9 (12.2%) are still in regular pediatric care
- 2 have been considered as not needing adult endocrine follow-up
- 4 are lost to follow-up before starting transition.

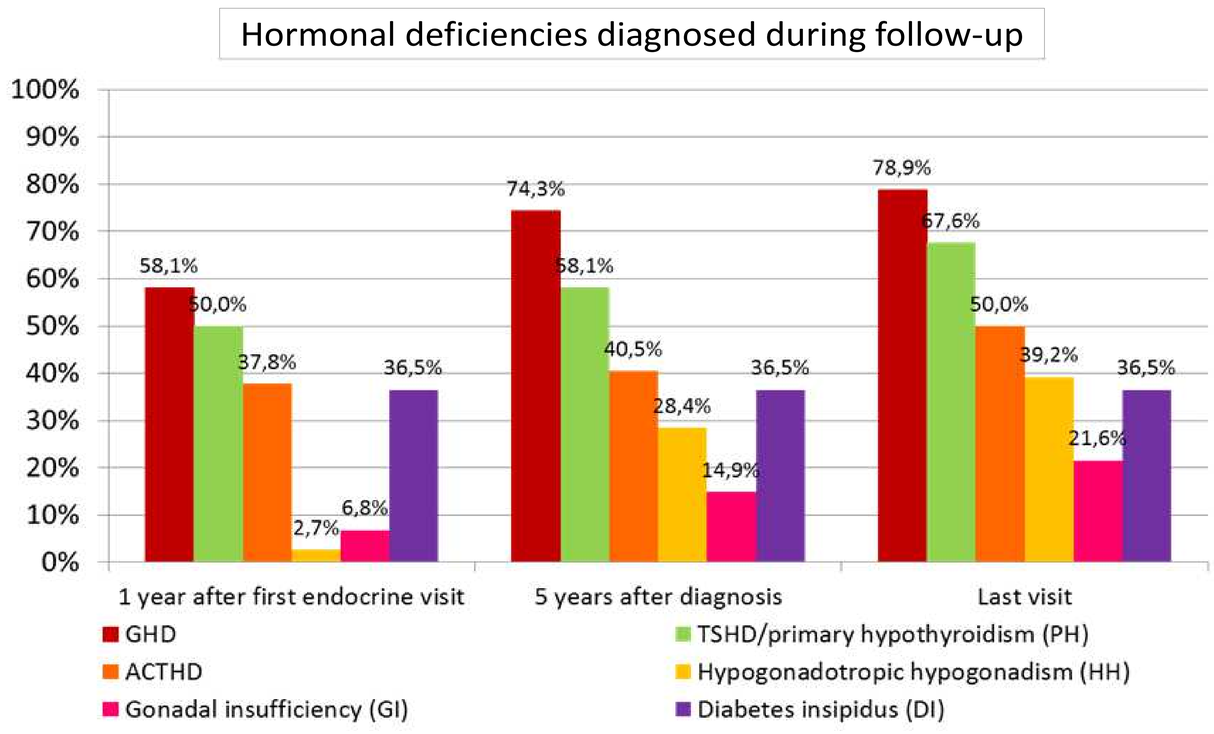
Forty-four out of 59 who started transition (74.5%) have been seen at La Pitié-Salpêtrière hospital or other adult centers in the last year.

Childhood onset growth hormone deficiency (CO-GHD), defined as GHD diagnosed before final height: 51/74 (68.9%).

At transition re-evaluation, 56/71 have GHD (T-GHD), with 11 new cases and 3 normalised GH responses in previously diagnosed CO-GHD (two of them in patients with little or no pituitary radiotherapy). 2 patients have not yet been evaluated at transition, 1 patient has unavailable GH testing data at transition.



Mean final height is significantly lower in patients with non suprasellar tumors: -0.8±1.3 SD compared to suprasellar: 0.1±1.4 (p=0.01).



TSHD or peripheral hypothyroidism (PH) concerns 75.7% of patients.

Routine thyroid ultrasound has been performed in 28 patients; 15 of them have thyroid nodules, including two thyroid cancers (5 and 12 years after RT).

ACTHD affects 50% patients.

Hypogonadotropic hypogonadism (HH) is present in 42% of patients, and gonadal insufficiency (GI) in 24%.

Diabetes insipidus affects only suprasellar tumors (28/39).

BMI is higher in patients with suprasellar tumors: 29.2±9.2 Kg/m2 (21% overweight, 39% obesity) than in non suprasellar: 22.6±3.9 Kg/m2 (14% overweight, 3% obesity), p<0.001.

27/57 reports a handicap (visual or neurological) that impairs their studies or work.

Conclusions: Transition is a critical time for patients with chronic diseases, including childhood brain tumor survivors. It is important to ensure an effective passage towards adult endocrine care, in order to maintain care continuity and prevent complications linked to non compliance to treatment. Our transition program between a pediatric and an adult hospital seems to contribute to this care continuum.

Supported in part by novo nordisk®