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Craniopharyngioma registry for adult patients, an initiative of the pituitary workgroup of the DGE

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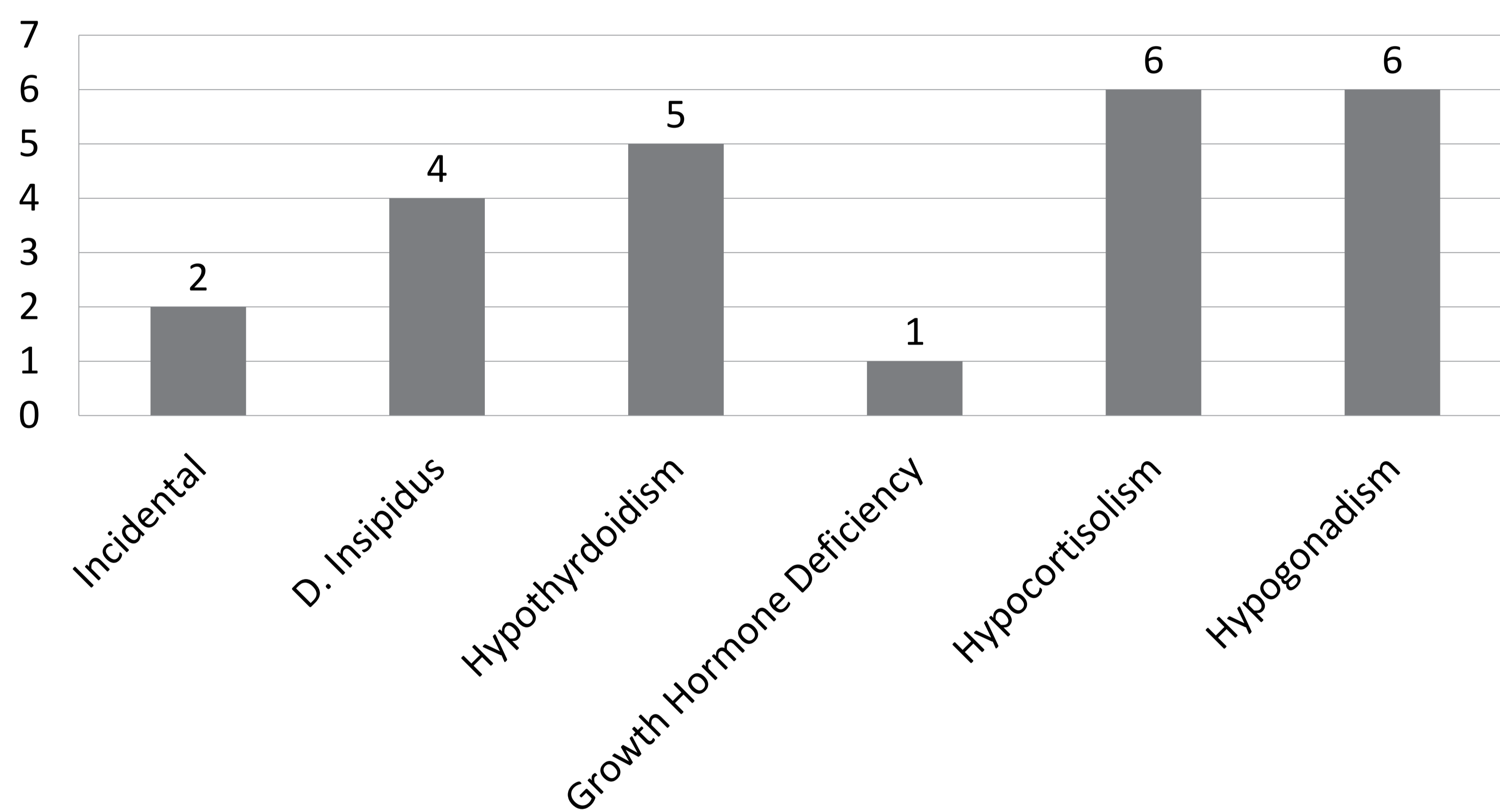
Introduction: Adult craniopharyngioma as a rare neoplasm of the central nervous system is still very poorly understood. The clinical implications for affected patients are numerous, ranging from endocrine dysfunction to visual loss and neurological impairment. Although the progress of this tumor entity is slow by nature, affected patients often suffer from multiple symptoms even after successful treatment with a strong impact on their individual quality of life. In order to achieve a better understanding of the course of the illness and the effect of modern treatment options a central registry for long-term observation of these patients is introduced by the pituitary workgroup of the DGE.

Methods: Based on the childhood craniopharyngioma registry already in place in Germany, modified case report forms (CRF) were developed to provide a better fit for disease related problems in the adult population. A standardized evaluation of the patients including MRI and CT Scans is performed, where location and dimensions as well as mass effects of the tumor are assessed. Each patient is requested to regularly fill out standardized QoL questionnaires. Regular follow ups, beginning 6 months postoperative and after that period according to the endocrinologist/neurosurgeon in charge shall ensure detailed data acquisition.

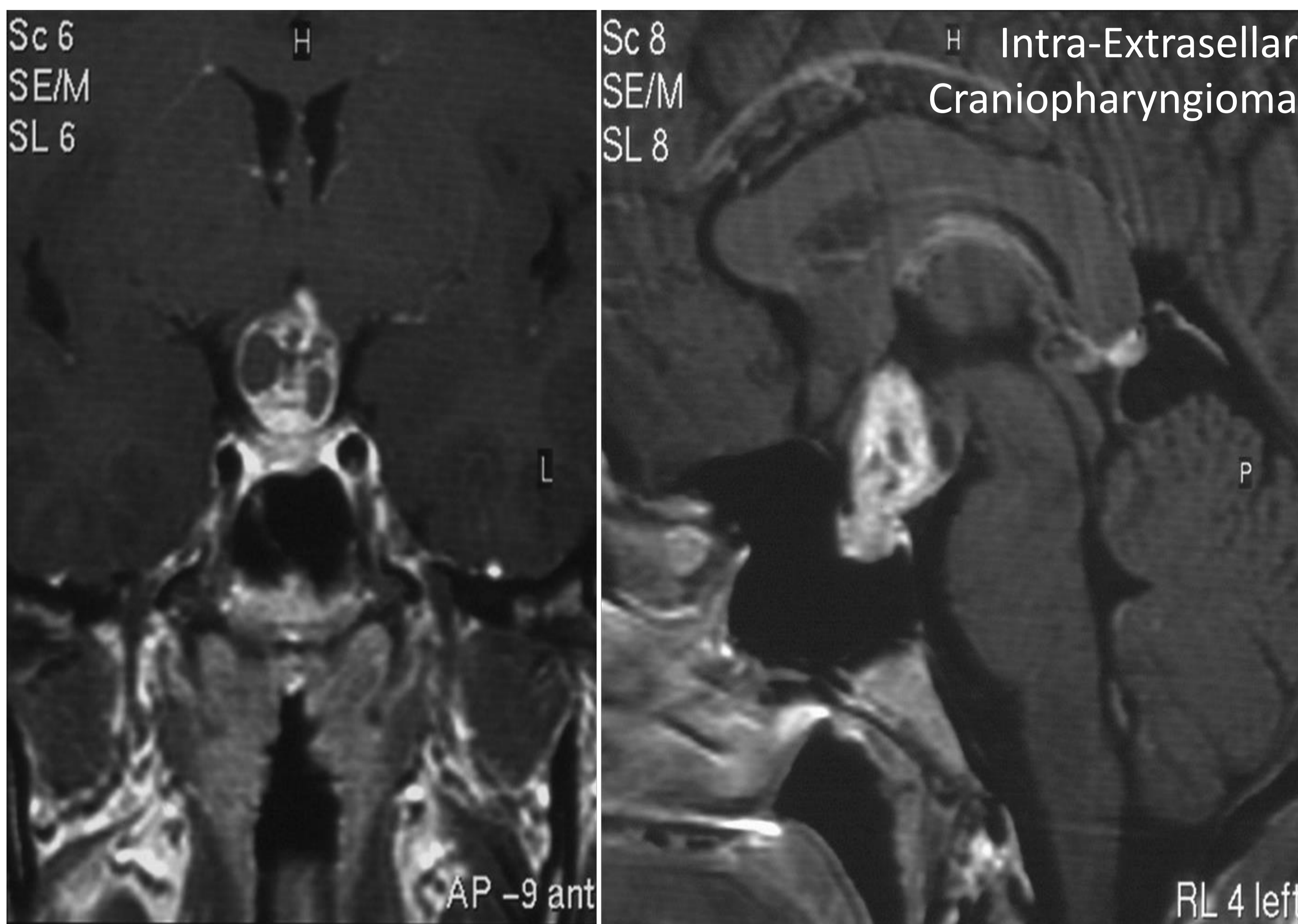
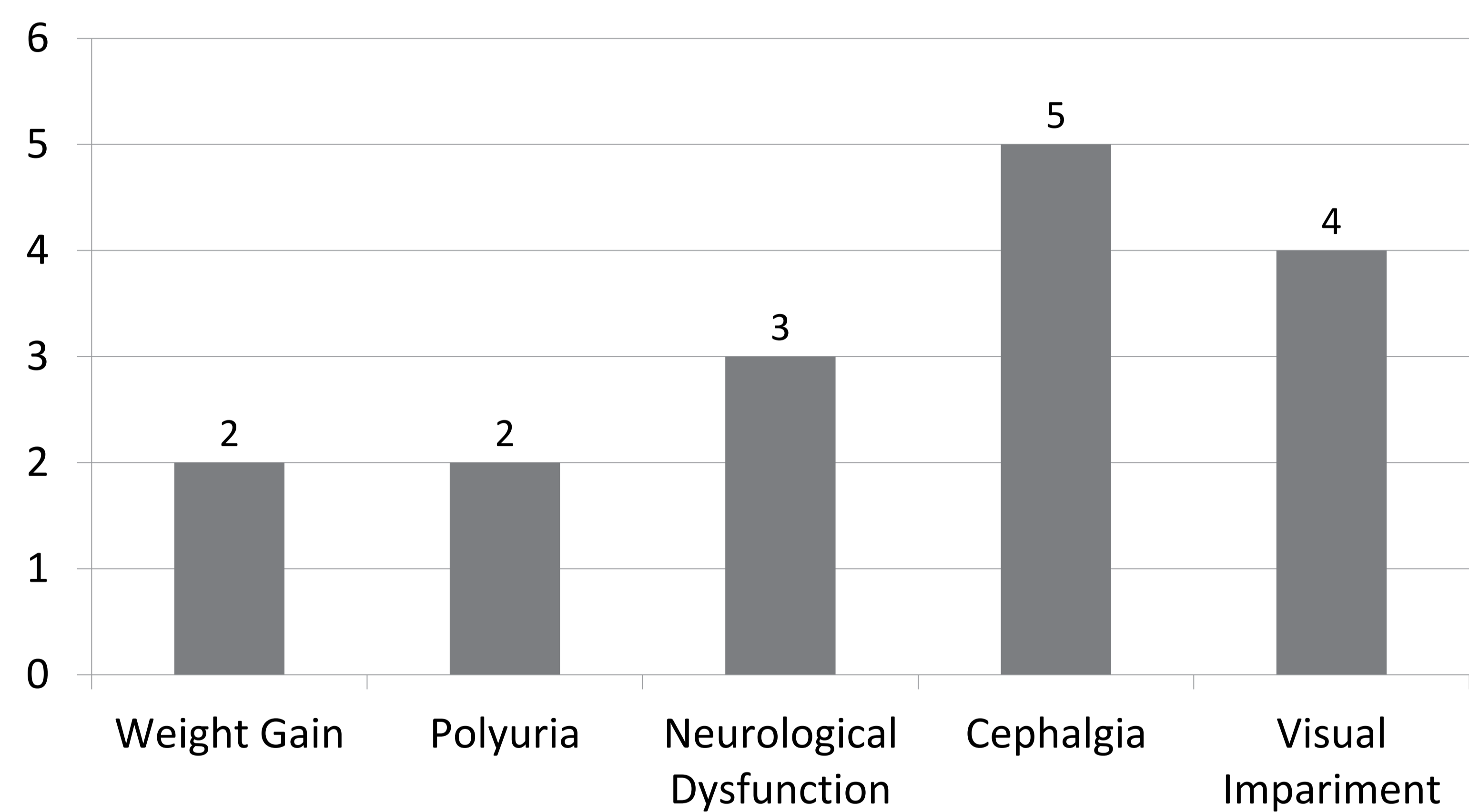
Radiographic Features	
Intracranial localization	17% intrasellar / 50% extrasellar / 33% intra and extrasellar
T1 Signal	50% hyperintense , 50% isointense
T2 Signal	67% hyperintense, 33% hypointense

General Preliminary Results	
Gender	2 male // 13 female
Age	mean 47.7 years, min 27 max 70
BMI	mean 23.6, min 17.6 max 34.7
Histology	6 adamantinomatous / 4 papillary / 5 pending

Affection of Pituitary Function



Presenting Symptoms



Conclusion: Due to the heterogeneity of craniopharyngioma concerning presentation and morphology, further patient recruitment and thorough clinical follow up is essential in order to refine the treatment of patients suffering from craniopharyngioma in the future.

Dateneingabe

Kraniopharyngiomdatenbank für erwachsene Patienten
Ein Projekt der AG Hypophyse der DGE

UKE002

Basisdaten | Präoperativ | Radiologie | Verlauf 1 | Verlauf 2

Code: UKE002

Erhebungsmodus: <input type="checkbox"/> Prospektiv	<input type="checkbox"/> Inzidenteller Befund	<input type="checkbox"/> Minirin/DDAVP	<input type="checkbox"/> Geplant	<input type="checkbox"/> Durchgeführt
ED Radiologie: 07.10.2014	<input type="checkbox"/> D. Insipidus	<input type="checkbox"/> L-Thyroxin	<input type="checkbox"/> Resektion	<input type="checkbox"/>
ED Histologie: 07.10.2014	<input type="checkbox"/> Sek. Hypothyreose	<input type="checkbox"/> Wachstumshormon	<input type="checkbox"/> Teilresektion	<input checked="" type="checkbox"/>
Datum Ersterhebung:	<input type="checkbox"/> Wachstumshormonm.	<input type="checkbox"/> Glucocorticoide	<input checked="" type="checkbox"/> Biopsie	<input type="checkbox"/>
Körperhöhe: 176	<input type="checkbox"/> Hypocortisolismus	<input type="checkbox"/> Sexualsteroid	<input type="checkbox"/> Zystendekompression	<input type="checkbox"/>
Körpergewicht: 55	<input type="checkbox"/> Hypogonadismus	<input type="checkbox"/> Lipidsenker	<input type="checkbox"/> Intracavitäre Instillation	<input type="checkbox"/>
Bauchumfang:	<input type="checkbox"/> Verhaltensauffälligkeit	<input type="checkbox"/> Psychopharmaka	<input type="checkbox"/> Shunt	<input type="checkbox"/>
RR Systolisch: 120	<input type="checkbox"/> Hypothalamische Syn.	<input type="checkbox"/> Melatonin	<input type="checkbox"/> Keine OP Beobachtung	<input type="checkbox"/>
RR Diastolisch: 70		<input type="checkbox"/> Antidiabetika	<input type="checkbox"/> Operations Datum: 11.03.2015	
Gewichtszunahme: <input type="checkbox"/> Dauer	HbA1C: 5,7	<input type="checkbox"/> Antihypertonika	<input type="checkbox"/> Operateur: Fli	
Polyurie: <input type="checkbox"/> Dauer	Insulin: 9	<input checked="" type="checkbox"/> OPSF36 Kurz	<input type="checkbox"/> Hypothalamusinfiltration	<input type="checkbox"/>
Neurolog. Defizite: <input checked="" type="checkbox"/> Dauer	Cholesterin: 220	<input checked="" type="checkbox"/> EORTCQLQC30_BN20	<input type="checkbox"/> Hypophysenstielhalt	<input type="checkbox"/>
	Dexa: <input type="checkbox"/>		Zuzug:	

Electronic Patient Registry

