# **SAT 488**

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### BACKGROUND

- Cushing's disease (CD) has an annual incidence of up to 8 per million in the US.<sup>1</sup>
- Uncontrolled CD leads to significant morbidity and mortality.<sup>2</sup>
- To diagnose Cushing's disease (CD) recurrence and mitigate increased morbidity/metal risks, long-term follow-up is essential. <sup>3,4</sup>
- Real-world follow-up interval patterns of patients with CD may supplement existing recommendations on appropriate follow-up of such patients with CD in clinical pract

## OBJECTIVE

 The aim of this study was to determine the length of time that had elapsed since the visit, in CD patients treated in the US.

## METHODS

#### **Study Design and Data Source**

- Retrospective data collected from medical records at 8 US pituitary/endocrine cente selected based on volume of CD patients, location, and patient diversity.
- The study was approved by institutional review boards.

#### **Patient Selection Inclusion Criteria**

- Diagnosed with CD or CD recurrence within past 20 years; AND
- $\geq$ 18 years old at diagnosis.

#### **Data Collection**

- Data (collected from onset of Cushing's Syndrome (CS) symptoms through 2014 by abstractors) included:
  - Demographics (age, sex, race/ethnicity)
  - Disease characteristics: onset of CS symptoms, date of diagnosis of CD, CD rec biochemical status
  - CD treatments delivered at study centers and local practices
  - Comorbidities (prevalence was based only on comorbidities reported at the study centers)
  - Final disposition (date of last visit, evidence of transfer of care, insurance status visit)
- Data quality measures included rigorous abstractor training, data quality checks, and up abstraction for inconsistencies and missing entries.

#### **Statistical Analysis**

- Descriptive results stratified by length of time since last visit: ≤1 year; 1-2 years; and >2 years.
- Analyses performed with SAS® version 9.4 (SAS Institute, Cary, NC).

## Follow-Up Intervals in Cushing's Disease: A Multi-Center Study in 230 Patients

\* Potential conflict of interest may exist. Please refer to the Meeting App.

	RESULTS		
	Patient and Follow-Up Characteristics	Table 1	
nortality	<ul> <li>Of the 230 patients studied, 124 (54%) were last seen ≤1 year, 42 (18%) within 1-2 years, and 64 (28%) were last seen &gt;2 years prior (Table 1).</li> </ul>	Chara	
tice.	<ul> <li>Transfer of care, with presumed follow-up elsewhere, was documented in 5 patients (4%) with a visit ≤1 year prior, 8 (19%) with last visit 1-2 years prior, and 23 (36%) with a last visit &gt;2 years prior (Table 1).</li> </ul>	N (%) Age at Media	
e last	<ul> <li>Patients with a last visit &gt;2 years prior (n=64) compared to those seen ≤1 year prior (n=124):</li> </ul>	Race, Black	
	<ul> <li>Were more likely to be female (89% vs. 74%)</li> </ul>	Other	
	• Had a lower comorbidity burden (median number of	Ethnic	
ers.	CONDITIONS: 4 VS. 5) $\sim$ Had similar proportions of insurad patients (80%)	No. of	
,	$\sim M/\alpha r \alpha \log (1000)$ in the loss of the second sec	Insura	
	pharmacotherapy (20% vs. 33%)	Recur	
	<ul> <li>Had similar median age (44 vs. 46 years) and race distributions (e.g., both 69% white)</li> </ul>	Time f (years)	
	<ul> <li>Recurrent or residual disease was most commonly observed in those seen ≤1 year (48%) than in patients last</li> </ul>		
	seen 1-2 years (29%) or >2 years prior (28%) (Table 1).		
y trained		<sup>a</sup> Percen <sup>b</sup> Based <sup>c</sup> From f	
currence,	Treatment for Cushing's Disease	Table 2	
	<ul> <li>96% had surgical excision as first-line therapy.</li> </ul>		
ly	<ul> <li>Among 89 patients with residual/recurrent CD, 45 (51%) received pharmacotherapy, 29 (33%) radiatiotherapy, and</li> </ul>	Patien	
at last	16 (18%) adrenalectomy.		
nd follow-	<ul> <li>Fewer patients with a last visit &gt;2 years prior had radiotherapy (11%) compared to those seen within 1 vear (41%) (Table 2)</li> </ul>	Phar Radia	
	<ul> <li>Median elapsed time from start of most recent type of</li> </ul>		
	therapy to last visit was shorter among patients last	Aure	

seen >2 years prior compared to those seen within 1 year, 8.1 vs. 14.9 months, respectively.

visit

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#### able 1. Patient Characteristics, by Follow-Up Interval

	Time since last visit		
cteristics	≤1 year	1-2 years	>2 years
	124 (54)	42 (18)	64 (28)
t last visit (years), mean $\pm$ SD	$46 \pm 13$	$45\pm14$	$44 \pm 13$
an [range]	46 [23-83]	43 [21-73]	44 [19-79]
<b>e</b> , n (%)	92 (74)	32 (76)	57 (89)
Caucasian, n (%) <sup>a</sup>	86 (69) 10 (8) 4 (3)	25 (60) 1 (2) 1 (2)	44 (69) 3 (5) 4 (6)
<b>ity</b> , Hispanic/Latino, n (%) <sup>a</sup>	23 (21)	6 (23)	12 (24)
<b>comorbidities</b> , mean $\pm$ SD <sup>b</sup>	$5.5\pm3.4$	$3.7 \pm 2.7$	$3.7\pm2.7$
nce status, Insured, n (%) <sup>a</sup>	109 (89)	39 (93)	55 (89)
rent/residual disease, n (%)	59 (48)	12 (29)	18 (28)
<b>rom diagnosis to last visit</b> ), median [range]	3.9 [0.0-27.4]	3.5 [0.0-18.8]	1.6 [0.0-21.7]
<b>/-up duration at study centers</b> ), median [range] <sup>c</sup>	2.7 [0.0-27.5]	1.5 [0.0-15.5]	1.1 [1.0-21.7]
nented transfer of care, n (%)	5 (4)	8 (19)	23 (36)

Percent among non-missing observations. Based on comorbidities reported at study centers. From first to last visit.

#### able 2. Treatment for Recurrent/Residual CD<sup>a</sup>

	Time since last visit		
atients with recurrent/residual CD	≤1 year	1-2 years	>2 years
o. (%) of patients	59 (66)	12 (13)	18 (20)
Pharmacotherapy	34 (58)	3 (25)	8 (44)
Radiotherapy	24 (41)	3 (25)	2 (11)
Adrenalectomy	11 (19)	1 (8)	4 (22)
<b>Time from last treatment to last visit</b> (months), median [range]	14.9 [0.0-196.2]	25.1 [0.0-137.0]	8.1 [0.0-94.0]

<sup>a</sup> Any therapies before last visit at study site.

#### Research was conducted by Partnership for Health Analytic Research, LLC.



### Data from outside the study centers may have been inconsistently captured.

Care at the study centers may not be representative of care throughout the US.

## CONCLUSIONS

- Many patients with CD went more than 1 year without a visit at these pituitary centers.
- A majority did not have transfer of care documented.
- Although follow-up elsewhere may have occurred without documentation, the absence of documentation itself may represent an opportunity for quality improvement efforts.
- The ideal period for follow-up of CD has not been established, although delay in follow-up may place patients at risk of undetected recurrence, progression, or development of comorbidities, unless appropriate care is received outside the study centers.

#### References

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