

# Letters

## RESEARCH LETTER

### Public Awareness of Cleidocranial Dysplasia After Season Releases of *Stranger Things*

Collectively, rare disorders affect approximately 400 million people worldwide, posing a significant medical and economic burden for both patients and the health care system.<sup>1</sup> Groups of patients with rare disorders have difficulty advocating for themselves owing to a lack of funds, outreach, or manpower. Solutions are thus needed to promote awareness.

Television portrayals of rare disorders may affect public awareness of these disorders, especially on shows with broad viewership. The Netflix original series *Stranger Things* features actor Gaten Matarazzo III, who was born with the rare disorder cleidocranial dysplasia (CCD), a disorder he shares with the character whom he portrays, Dustin Henderson. The most prominent features of CCD—absent or abnormal bone growth of the clavicles and teeth—have been featured in scenes in which Dustin educates his peers about his disorder. In this study, we used Google Trends and CCD-related foundation website data to investigate the association of television portrayals of CCD with public interest and awareness of the disorder.

**Methods** | Using Google Trends, on July 16, 2019, we searched, downloaded, and retrospectively analyzed the relative search interest for CCD relative to release dates of *Stranger Things*. We searched worldwide using the “health” query category with the keywords *cleidocranial dysplasia*. Data were collected for a 5-year period from July 20, 2014, to July 16, 2019 (eTable in the Supplement). Because this study does not constitute human participants research, it was exempt from approval by the Oklahoma State University Center for Health Sciences institutional review board.

We also contacted CCD-related foundations (Children’s Craniofacial Foundation, AboutKidsHealth, and FACES: The Na-

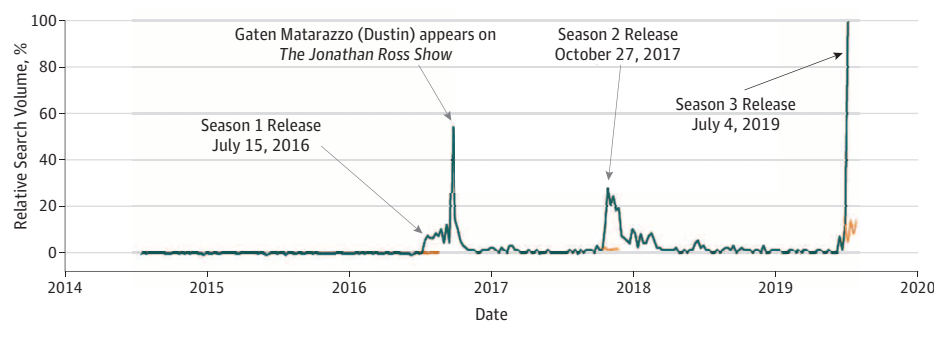
tional Craniofacial Association) to determine call volumes or website traffic after the release of each season of *Stranger Things*. Expected forecasting was performed using an autoregressive integrated moving average model (R, version 3.2.1; R Project for Statistical Computing). Relative search interests of less than 1 were assigned a value of 0.5 to allow for trend forecasting. All other analyses were conducted using Stata, version 15.1 (StataCorp LLC).

**Results** | Relative search interest for CCD demonstrated an increase of 94.4% (95% CI, 90.3%-98.6%) above the expected search interest the week after the release of the most recent season of *Stranger Things* (season 3). A mean increase of 11.2% (95% CI, 3.8%-18.6%) was noted after season 1, and an increase of 12.9% (95% CI, 6.8%-19.0%) was seen after season 2 (Figure 1). In addition, all contacted CCD-related foundations reported an increase in public interest about CCD after the release of *Stranger Things*; however, only data from AboutKidsHealth were quantifiable. Before the release of *Stranger Things*, AboutKidsHealth reported a mean of 5 to 80 CCD-related website page views per week.<sup>2</sup> The week after the release of season 3, website traffic to CCD-related pages reached 10 000 visits (Figure 2).

**Discussion** | The release of each season of *Stranger Things* has been associated with an increase in weekly search interest for CCD above expected. Since the introduction of CCD on *Stranger Things*, Matarazzo helped establish the foundation CCD Smiles to promote global awareness, provide dental care assistance, and support research.<sup>3</sup> Through their expansive reach to the public and media connections, celebrities such as Matarazzo may serve as positive agents to raise awareness and educate the general public.<sup>4</sup>

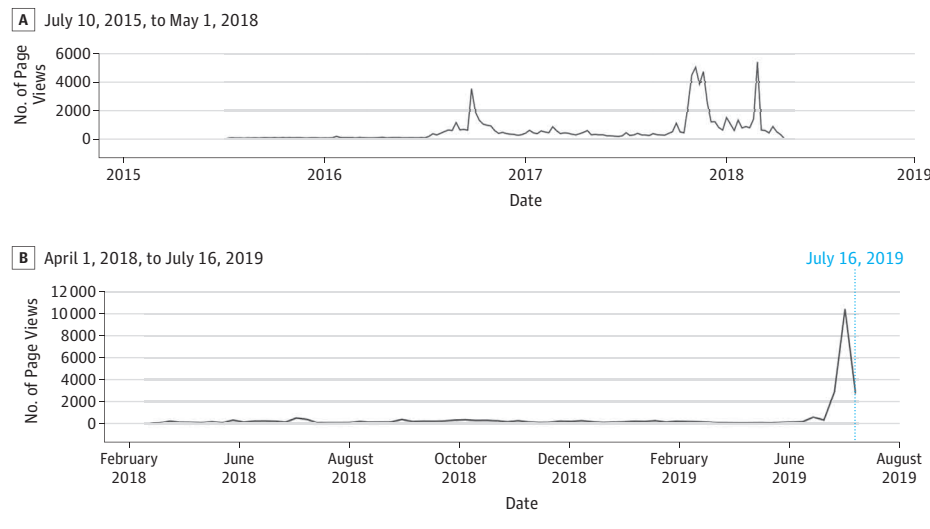
Similarly, raising awareness has been shown to increase research funding, ameliorate early diagnosis, expand treatment options, broaden coping strategies, reduce feelings of isolation or discrimination, and improve overall quality of life for those with rare disorders.<sup>5</sup> The media also have the unique opportunity to serve as a catalyst to correct public misperceptions and to foster accurate portrayals of rare disorders. The Entertainment In-

Figure 1. Relative Search Interest for Cleidocranial Dysplasia After the Release of *Stranger Things*



Observed weekly search interest in cleidocranial dysplasia (blue curve) vs expected search interest forecasted if *Stranger Things* was never released (orange curve). Expected forecast was calculated using an autoregressive integrated moving average model.

Figure 2. AboutKidsHealth Website Traffic on Cleidocranial Dysplasia Information Web Page



A, Website traffic on cleidocranial dysplasia information web page from July 10, 2015, to May 1, 2018. An increase in website traffic was associated with the release dates of *Stranger Things* season 1 (July 15, 2016) and season 2 (October 27, 2017). B, Website traffic on cleidocranial dysplasia information web page from April 1, 2018, to July 16, 2019. An increase in website traffic was associated with the release date of *Stranger Things* season 3 (July 4, 2019).

dustries Council develops guides for writers and producers to enable accurate portrayals of characters with disorders. To our knowledge, no guide currently exists for CCD or for many other rare disorders.<sup>6</sup> Thus, although it is important for writers to exercise caution when portraying characters with rare disorders, inclusion of such characters in the mainstream media may be a beneficial strategy to raise awareness of them.

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## State-Sponsored Price Transparency Initiatives for Otolaryngologic Procedures in 2019

Many recent initiatives to reduce health care spending have focused on price transparency (PT). Given that health care prices vary substantially and there is no clear association between price and quality, PT may enable consumers to seek lower-cost services and stimulate competition between clinicians.<sup>1</sup> Furthermore, PT may serve as an important means of facilitating access to affordable care as more Americans subscribe to high-deductible plans.<sup>1,2</sup>

State-sponsored initiatives are among the most promising means of facilitating PT. States can obtain comprehensive market data to provide all patients with robust price information. By contrast, price information reported by health plans, consumer groups, and clinicians is more limited in scope and audience (eg, health plan subscribers).<sup>2</sup> Little is known about how these initiatives may inform the care of patients seeking otolaryngologic care. We therefore sought to characterize the information provided by state-sponsored PT websites for outpatient otolaryngologic procedures.