**Background/Purpose:**

Disease and treatment burdens are high for children living with rheumatic diseases. Pediatric patients and their families lack a mature evidence base to guide treatment decisions and often need higher levels of psycho-social support that may not be available in traditional healthcare settings. In this context, engaging others facing similar challenges and health problems via social media may be helpful and impactful for healthcare decision making.

In this study, we sought to understand attitudes, beliefs, and behaviors concerning social media use among parents of children with rheumatic diseases.

**Methods:**

We worked with PARTNERS, a patient-powered research network, to disseminate an online survey through nine patient support groups that help families with children with rheumatic diseases. The survey was distributed through email links, on websites, and on these groups’ social media accounts. Surveys were completed anonymously under implied consent between January 22 - April 20, 2019. The study was deemed exempt by the Boston Children’s Hospital IRB.

Parents responded to questions about their child’s rheumatic disease diagnosis and disease activity, use of social media, child’s health (PROMIS Parent Proxy Scale v1.0 - Global Health), parent’s global health (PROMIS Scale v1.2 - Global Health), and perceived availability of helpful information or advice (PROMIS Item Bank v2.0 - Informational - Short Form). Exclusion criteria are seen in Figure 1. Child’s health was classified as “good” if child’s Global Health T-scores was ≥ 40; it was “poor” if child’s Global Health T-score was < 40.

**Results:**

712 participants were included in the current analysis. Participant characteristics are shown in Table 1. Child’s health and disease activity varied significantly depending on the child’s diagnosis. Disease activity, as noted by the parent, are shown in Figure 2.

**Conclusion:**

- **Health-related social media use by parents of children with rheumatic diseases** was widespread in this large cohort of parents recruited online through patient support organizations. Virtually all parents had accessed Facebook to read about other families with children with rheumatic diseases. The greatest benefit from online interactions resulted from decreasing feelings of isolation of the parent and normalizing the diagnosis of a rheumatic illness in a child.

- **Online interactions translated into behavior changes, managing medication, child’s symptoms, medication side effects, as well as the social and mental health issues that accompany the disease.** Most half of parents had accessed Facebook to read about other families with children with rheumatic diseases.

- Despite a somewhat sicker patient population in this cohort than the average rheumatic disease population, parents were slightly more likely than the US population to feel they have access to helpful information, perhaps because of their use of social media and patient support organizations.

An important limitation of our findings is that participants were recruited from social media and patient support organizations, likely biasing for a more engaged population; results may not generalize to the broader population of children with rheumatic diseases. However, the vast number of responses for very rare diseases suggests we were able to capture a substantial proportion of the rare subset of children with rheumatic diseases. A better understanding of parental needs may allow us to create interventions that could help provide greater support for families and improve health outcomes for children with rheumatic diseases.