

The Global COVID-19 Observatory and Resource Center for Childhood Cancer: A response for the pediatric oncology community by SIOP and St. Jude Global

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Abstract

The COVID-19 pandemic quickly led to an abundance of publications and recommendations, despite a paucity of information on how COVID-19 affects children with cancer. This created a dire need for a trusted resource with curated information and a space for the pediatric oncology community to share experiences. The Global COVID-19 Observatory and Resource Center for Childhood Cancer was developed, launched, and maintained by the International Society of Pediatric Oncology and St. Jude Children's Research Hospital. The three components (Resource Library, Global Registry, and Collaboration Space) complement each other, establishing a mechanism to generate and transfer knowledge rapidly throughout the community.

KEYWORDS

collaboration, COVID-19, knowledge transfer, pediatric oncology

Abbreviations: GCORCCC, The Global COVID-19 Observatory and Resource Center for Childhood Cancer; SIOP, International Society of Pediatric Oncology; SJCRH, St. Jude Children's Research Hospital.

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1 | INTRODUCTION

After rapidly spreading across the globe, COVID-19 officially became a pandemic on March 11, 2020.¹ Initial reports suggested that patients with comorbidities were at higher risk, causing concern that children with cancer were at risk of developing severe infection.² Furthermore, measures to mitigate the spread of the virus, such as delaying medical procedures and travel restrictions, were anticipated to disturb the continuity of pediatric cancer care.³ It was also anticipated that the effects of the pandemic on health systems would amplify existing obstacles to caring for children with cancer.³

Since the beginning of the pandemic, a deluge of information regarding disease characteristics and possible management strategies was disseminated. This infodemic, an overabundance of information during an epidemic,⁴ has posed challenges never encountered before and was an early concern.⁵ The rapid spread of information and misinformation, potentiated by social media platforms, presented a public health challenge, confusing and overwhelming healthcare professionals and lay public alike.

In response to the need for a trusted resource with curated, reliable information and a platform to share experiences for the pediatric oncology community, the International Society of Pediatric Oncology (SIOP) and St. Jude Children's Research Hospital (SJCRH) created the Global COVID-19 Observatory and Resource Center for Childhood Cancer (GCORCCC). The GCORCCC was launched as an open-access website (covid19childhoodcancer.org) on April 15, 2020.

2 | GENERAL OVERVIEW OF THE RESOURCE CENTER

The GCORCCC comprises three main elements: Resource Library, Global Registry, and Collaboration Space, outlined below. As of October 20, 2020, the GCORCCC has 64,980 page views by 32,295 unique

users from 164 countries (Figure 1). Additionally, to address questions related to pediatric cancer care during the pandemic in a live and interactive way, a series of webinars entitled *COVID Conversations* have been hosted. To date, 11 sessions directed at various aspects of cancer care and disciplines, including pediatric oncologists, nurses, surgeons, radiation oncologists, nongovernmental organizations, parents, and survivors, have been held. Regionally focused sessions were also held for Northern Italy and Spain, India and Pakistan, Latin America, and Africa. On average, the webinars have been attended by 337 people from 70 countries.

2.1 | Resource library

The Resource Library contains updated curated peer-reviewed manuscripts, guidance documents, and links relevant to the multidisciplinary care of children with cancer during COVID-19.⁶ Publications are reviewed and assessed for relevance weekly for inclusion.⁷ We prioritize the dissemination of accurate data and quickly identify and address misinformation or conflicting reports. Only peer-reviewed articles are included, as unvetted scientific information, such as preprints, were identified as a risk for misinformation for providers.⁸⁻¹⁰

The sections of the Resource Library are as follows: COVID-19 and Pediatric Oncology, General COVID-19 Information, Treatment, Prevention, For Healthcare Providers, and For Patients and Families. Each section provides a collection of publications, guidance documents, recorded webinars, and relevant links.

To address the needs of healthcare professionals during this unprecedented time, resources focusing on leadership, self-care, and resiliency are also included in the Resource Library. Additionally, a subsection specifically aimed at nurses, with literature and guidance documents, was developed. The *Pediatric Oncology Nursing during COVID-19 Fact Sheet* summarizes the most relevant guidance for caring for chil-

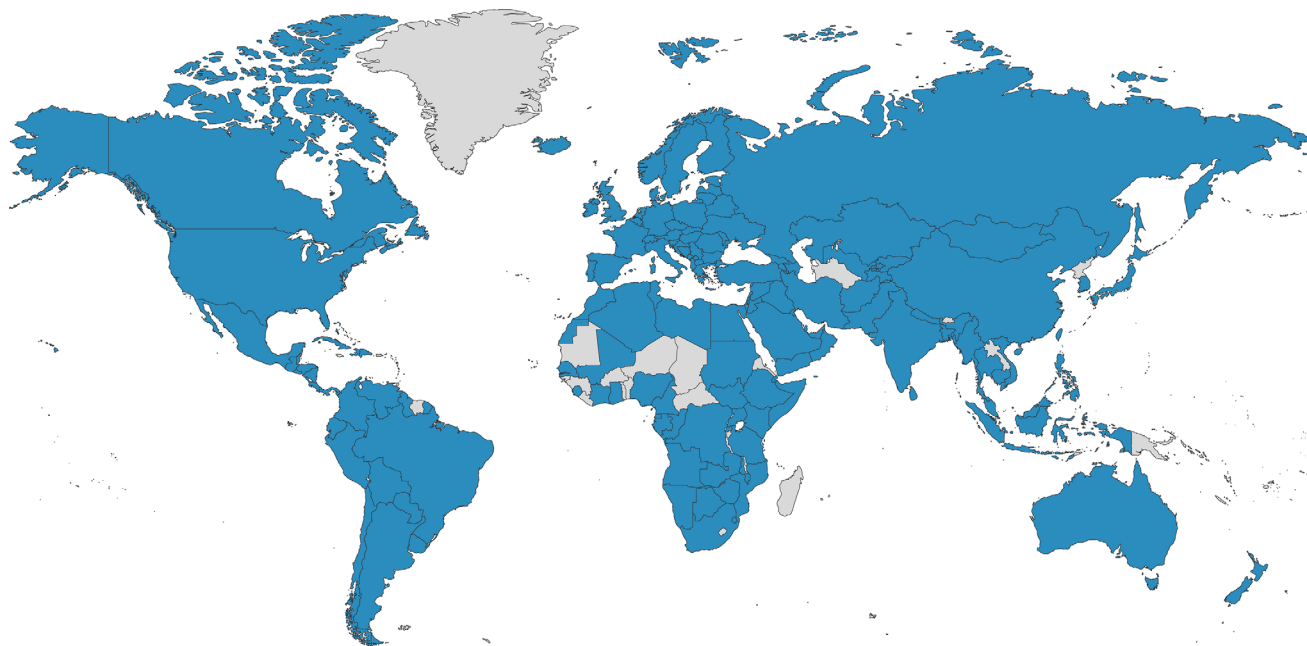


FIGURE 1 Global COVID-19 Observatory and Resource Center for Childhood Cancer usage
Individuals from more than 160 countries from across the world accessed the GORCCC

dren with cancer and is available in six languages as a quick bedside reference. Finally, a section with resources for patients and families aids bedside providers in educating and navigating patients and families toward trusted, accurate sources of information.

2.2 | Registry

At the beginning of the pandemic, the natural history of COVID-19 in children and adolescents with cancer was unknown. To gain an accurate picture of the burden of COVID-19 among this patient population, we developed the Global COVID-19 Registry. Healthcare providers worldwide were invited to voluntarily report any patient (under 19 years of age) with a malignancy or history of hematopoietic stem cell transplant at the time of a laboratory-confirmed SARS-CoV-2 infection. The Registry was approved by the SJCRH Institutional Review Board.

As of December 21, 2020, 1228 cases from 46 countries have been reported. Using aggregate data, we created an interactive data visualization dashboard to provide updates in a dynamic format (Figure 2). The data visualization allows providers to filter cases by variables such as underlying diagnosis, cancer treatment, and COVID-19 outcomes.

2.3 | Collaboration space

Creating an opportunity to bring the global community of healthcare professionals together is an essential component of the GORCCC. The Collaboration Space provides a forum for healthcare professionals to interact and share their experiences and questions about caring for

children with cancer during the COVID-19 pandemic. The Collaboration Space has language translation capabilities, making it accessible to a large number of providers globally. Here, users are also able to access content, such as videos, blog posts, and live events.

Through sharing experiences, providers can support and learn from each other. *From the Frontlines* is a blog series published to highlight unique accounts of childhood cancer providers navigating COVID-19 around the world. To date, the blog features stories from 24 providers in 19 countries. These providers discuss the challenges their teams have faced and innovative solutions they have employed to continue to treat children with cancer during the pandemic. Currently, there are 1300 total active users registered in the Collaboration Space who have connected and interacted over 36,000 times with content elements.

3 | DISCUSSION

A rapidly evolving pandemic poses many challenges in caring for children with cancer. The GORCCC established a mechanism to generate and transfer knowledge for the pediatric oncology community during a global pandemic and infodemic. Through its various elements, users can access relevant information to help them adapt and respond to the rapidly shifting situation.

Academic institutions and professional societies should play central roles in the accurate and timely dissemination of information. For professionals caring for children with cancer, the sharing of experiences from regions that were affected early in the pandemic was essential for formulating the initial responses to the evolving pandemic.¹¹⁻¹³ In addition, guidance for the management of COVID-19 for different

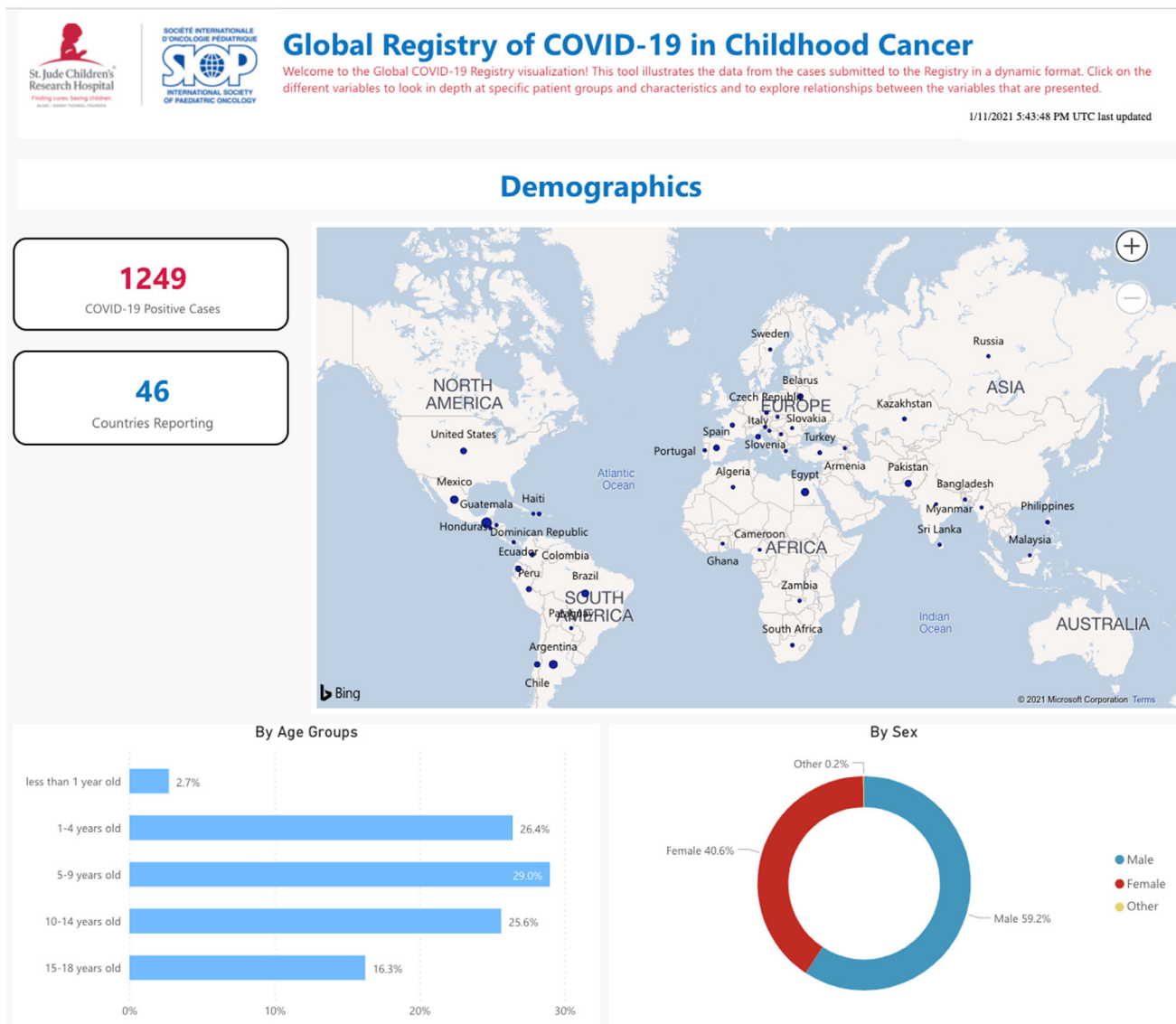


FIGURE 2 Screenshot of the visualization dashboard of the Global COVID-19 Registry. An interactive visualization was created to illustrate cases included in the Registry. Patients from 46 countries have been submitted (size of circle is proportional to patient number)

patient populations was generated by government agencies and professional societies with remarkable speed.¹⁴⁻¹⁶ Importantly, information sufficiency has been linked to less stress and worry amongst health care professionals.¹⁷ For this reason, a resource like the GCORCCC can support individuals to decrease burn out and improve resilience. This effort brought colleagues together and facilitated a sense of community in these trying times, in an innovative approach to addressing global challenges in pediatric cancer care. Many organizations attempted to compile listing of resources that are relevant to their specific populations, but few of them also sought to create knowledge about COVID-19 in their populations to add to the evidence-based literature.

4 | CONCLUSION

At a time of exceptionally high stakes for children with cancer, the multi-stakeholder collaboration that led to the GCORCCC represents a framework for global cooperative efforts in the future. SIOP and SJCRH formed a partnership aimed at disseminating the GCORCCC widely and rapidly throughout the global network, leveraging the strengths of both organizations. This platform shows that novel, dynamic information resources can help provide guidance to frontline providers across the globe, facilitating the rapid sharing and adoption of new information in highly dynamic situations. The collaborations built through this rapid multidisciplinary implementation and global dissemination process provide a foundation upon which the global

community can collectively build to ultimately improve outcomes for all children with cancer everywhere.

In memoriam: This manuscript is dedicated to Dr. Arturo Moreno, past president of SLAOP/SIOP Latin America, a tireless advocate for children with cancer in Mexico, Latin America, and the world.

CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

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