2020 COVID-19 Erdheim-Chester Disease Patient Survey

Results & Conclusion

Ninety-six (96) ECD patients from seven (7) different countries responded to the COVID-19 survey conducted by the ECD Global Alliance. In addition to the survey, 11 of the 33 ECD Referral Care Centers submitted survey data for this research. From all the responses, only one ECD patient reports as having had COVID-19, with this occurring before widespread knowledge of COVID-19 risks and safety measures were known. Although the patient did require ICU care, we are happy to report recovery did occur.

Unfortunately, becoming infected with the virus is not the only way this pandemic can affect patients. Fifty-six percent of responding patients have experienced impacts to their treatments and life as a result of the pandemic. This includes medical testing/follow up appointment delays (approximately 40%), treatment delays (approximately 12%), physical/occupational therapy delays (5%), and other social/economic impacts. In addition, care centers reported some delays in new patient referrals, non-urgent follow-up appointments and procedures, and less frequently, treatment changes or delays.

More detailed results of the patient survey can be found in the table on the following page.

Finally, one additional piece of good news came to light with the survey results. Approximately 1/3 of ECD patients have had at least one of their medical appointments converted from a face-to-face appointment to a virtual telehealth appointment. **The ability for doctors and patients to participate in a telehealth appointment can help to reduce travel time and costs, improve remote monitoring of patients and potentially expand the number of patients who have access to ECD Care Centers in the future.** Telehealth requires ongoing improvement in communication technology, government and payor buy-in, and greater reliance on local clinics for vital sign checks, labs and non-complex imaging studies. The ECD community is excited that the use of telehealth appointments can ultimately allow more options for patients to receive the best medical care possible.

Thank you to Drs. Paul Hendrie, Eli Diamond and Juvianee Estrada-Veras for their work in making this survey possible for the ECD community.

ECD GLOBAL ALLIANCE

Supporting those affected by Erdheim-Chester Disease worldwide.

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ECDGA COVID-19 Patient Survey

Question	# responding	% of total responders
# patients Responding	96	
# who were tested for COVID-19	7	7.29%
# who developed COVID-19	1	1.04%
# in hospital for COVID-19	1	1.04%
# patients reporting COVID-19 impacted treatment and life	54	56.25%
Lost Insurance	1	1.04%
Forced to self purchase treatment drugs	1	1.04%
Treatments delayed/cancelled	9	9.38%
Medical appointments/testing delayed/cancelled	19	19.79%
Forced Retirement	1	1.04%
Additional Social Isolation	25	26.04%
Anxiousness / confusion / mental health issues	4	4.17%
General cautiousness (following guidelines)	4	4.17%
Telehealth / home treatment	6	6.25%
Lack of exercise	1	1.04%
Busier with work, helps avoid feelings of isolation	1	1.04%
# with delayed follow ups to include treatment denial, imaging, biopsies, blood work, general medical appointments, and receiving test results	37	38.54%
# with actual delayed treatments	12	12.50%
# responding with treatment delays (some responses seemed focused on testing or PT/occupational)	17	17.71%
# who converted Telehealth	30	31.25%