RARE CANCER TOOLKIT

THE REALITY OF RARE CANCER

Consider a dozen statistics that shed further light on the unacceptable disparities:

1. Every pediatric-specific cancer is rare. The average age at diagnosis is 8.[1]

2. In 2017, 15,780 children received cancer diagnoses.[2]

3. Over 95% of pediatric cancer survivors will experience a significant side effect of cancer treatment by the age of 45.[3]

4. As of 2017, only one targeted therapy was approved for a cancer which disproportionately affects children.[4]

5. Prostate cancer, with a five-year cure rate nearing 100%, receives National Cancer Institute funding amounting to well over half the funding received for all childhood cancers combined.[5]

6. Pediatric care centers face critical drugs shortages due to lack of sufficient economic incentive for developers and manufacturers.[6]

7. Cancer is the leading cause of death among Asian Americans, Native Hawaiians, Pacific Islanders, and Hispanics.[7]

8. African Americans have the highest mortality rate of any racial and ethnic group for all cancers combined.[8]

9. Non-white patients are severely underrepresented in clinical studies. From 2015-2016, 76-79% of participants were Caucasian, 11-12% were Asian, and 5-7% were African American.[9]

10. Over 60 cancers disproportionately affect veterans and the military. Almost two-thirds of those cancers are rare.[10]

11. In 2018, only 25 cancers which disproportionately affect service members had an FDA-approved targeted therapy. The remainder are typically treated by surgery, radiation, and chemotherapy.[11]

12. Seven common cancers including breast, lung, and colorectal are actually composed of 12 types of non-rare cancers, and 103 forms of rare cancer, totaling over a quarter million diagnoses each year.[12]

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1 General Information About Rare Cancers of Childhood (n.d.). https://www.cancer.gov/types/childhood-cancers/hp/rare-childhood-cancers-pdq#_105/; Avg Age: NCI, SEER Age-Specific Rates and Counts for Cancer Sites by Single Year of Age at Diagnosis, Table 28.13 http://seer.cancer.gov/csr/1975_2012/results_single/sect_28_table.13_2pgs.pdf

2 NCI, SEER Age-Specific Rates and Counts for Cancer Sites by Single Year of Age at Diagnosis, Table 28.13 http://seer.cancer.gov/csr/1975_2012/results_single/sect_28_table.13_2pgs.pdf

3 St. Jude Children's Research Hospital, (JAMA. 2013:309 [22]: 2371-2381)
4 "Rare Isn't Rare", American Association of Cancer Researchers, Abstract 7739, Chicago, 2018.

5 American Cancer Society. "Current Grants by Cancer Type," March 1, 2020. https://www.cancer.org/research/currently-funded-cancer-research/grants-by-cancer-type.html.

6 "What's Causing a Shortage of Pediatric Cancer Drugs?", PBS, February 12, 2012, https://www.pbs.org/ newshour/show/what-s-causing-a-shortage-of-pediatric-cancer-drugs"

7 "Leading Causes of Death in Males, 2015", CDC, https://www.cdc.gov/healthequity/lcod/men/2015/ race-ethnicity/index.htm, "Leading Causes of Death in Females, 2015", CDC, https://www.cdc.gov/ women/lcod/2015/race-ethnicity/index.htm

8 LaFrance, A. "Poor Kids With Cancer Relapse Earlier Than Rich Children." The Atlantic. March 2016. Retrieved from https://www.theatlantic.com/health/archive/2016/03/poverty-children-cancer/473607/

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10 "Rare Isn't Rare", American Association of Cancer Researchers, Abstract 7739, Chicago, 2018. 11 SHEPHERD internal research.
12 SHEPHERD internal research.

THAT THE NEGLECTED *MAY* LIVE