

**Sleep Research Society
Advocacy Successes Summary
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The Sleep Research Society (SRS) continues to lead efforts to advocate for additional funding for federal sleep research activities. Coordinated ongoing congressional and administration outreach coupled with strong funding applications have led to significant enhancement of sleep research portfolios over recent years. SRS has also begun successful efforts to reinvigorate public health activities on sleep disorders and healthy sleep. Below, please find a recent summary of major advocacy initiatives.

- Over recent years, the sleep research portfolio at the National Institutes of Health (NIH) has more than doubled in size from \$233 million in FY 2014 to more than \$520 million today. These funding increases far outpace annual growth in NIH’s overall budget and now reflect ongoing investigator-initiated research projects at nearly every NIH Institute and Center.

Research/Disease Areas (Dollars in millions and rounded)	2015	2016	2017	2018	2019	2020	2021	2022	2023 Estimated	2024 Estimated
Chronic Disease	\$76	\$22	\$182	\$181	\$182	\$148	\$148	\$188	\$188	\$181
Sleep Research	\$313	\$315	\$327	\$352	\$436	\$461	\$493	\$520	\$544	\$555
Small Pox	\$17	\$49	\$57	\$13	\$10	\$13	\$20	\$37	\$39	\$39
Social Determinants of Health	+	+	+	+	+	\$3,058	\$3,407	\$4,075	\$4,266	\$4,374
Spina Bifida	\$10	\$12	\$13	\$14	\$16	\$18	\$16	\$17	\$18	\$18
Spinal Cord Injury	\$82	\$71	\$77	\$78	\$103	\$101	\$101	\$101	\$110	\$111
Spinal Muscular Atrophy	\$11	\$10	\$11	\$12	\$13	\$8	\$9	\$10	\$10	\$10

<https://report.nih.gov/funding/categorical-spending#/>

- In Fiscal Year 2021, SRS led community efforts to establish the Chronic Disease Education and Awareness (CDEA) Program and the Centers for Disease Control and Prevention with an initial investment of \$1.5 million. This program provides cooperative agreements to stakeholder organizations for public health work in condition specific areas and is now supporting a project in obstructive sleep apnea. CDEA is now funded at \$4.5 million annually and supports multiple communities.
- Congress directs medical research led by the Department of Defense (DoD) through the Peer-Reviewed Medical Research Program and its annual list of conditions deemed eligible for study. *Sleep* was included in the first-ever eligible conditions list and has been eligible to participate in the program ever since (*Sleep Disorders and Restriction* is currently listed), leading to the DoD becoming a major catalyst of sleep research. This

program was initially supported at \$20 million for the eligible conditions to compete for but has grown to \$370 million today.

- SRS continues to participate in community efforts to bolster research activities through the VA's medical and prosthetic research program, as part of the Friends of VA Research. The VA research program is now funded at nearly \$1 billion (and regularly supports sleep specific efforts in the areas of fatigue, PTSD, and mental health).
- As a result of community advocacy, Congress includes instructions and recommendations with research and public health funding each year. Below, please find the most recent congressional language on sleep from the FY2023 and 2024 appropriations processes.

Sleep Disorders.—The Committee applauds NHLBI and other NIH Institutes and Centers for the ongoing commitment to sleep and circadian research, and notes the wealth of opportunities for further progress in specific sleep disorders and the promotion of sleep health. The Committee encourages the National Center for Sleep Disorders Research [NCSDR] to advance the blueprint for on-going and emerging activities outlined through the recent NIH Sleep Research Plan and to advise the Committee of any resources, infrastructure, or innovation needed to facilitate further progress.

Kleine-Levin Syndrome.—The Committee commends NIH for its December 2021 publication of the Sleep Research Plan. The Committee encourages the inclusion of Kleine-Levin Syndrome [KLS], a complex neurological disorder characterized by long, recurring episodes of excessive sleep and derealization, as a sleep disorder requiring attention and study in the next publication of the Sleep Research Plan. The cause of KLS is still unknown, and there are no known treatments. Because KLS shares symptoms with other sleep disorders and mental health conditions, the Committee encourages NIH to expand its support for research about KLS, which could provide the KLS community and many others with critical information and answers.

Chronic Disease Education and Awareness [CDEA] Program.— The Committee is pleased with the administration of the CDEA program and includes \$4,500,000 for fiscal year 2024 to support existing and additional grants for chronic health conditions that do not have line item in CDC's budget. The CDEA program is supporting several important multi-year projects that are improving public and professional awareness, and the Committee urges CDC to continue to support these activities along with new initiatives.

NIH Sleep Research Plan.—The Committee commends the National Center on Sleep Disorders Research (NCSDR) for the release of the NIH Sleep Research Plan and supports the full implementation of the Plan. The Committee specifically encourages strong consideration of the Plan's proposal for multi-center studies and clinical trials.

Sleep Health and Health Disparities.—The Committee applauds ongoing and emerging efforts by NIMHD to advance health equity and address health disparities, including cross-Institute initiatives and the initiatives identified by the recent Minority Health and Health Disparities Research Framework. The Committee notes the disproportionate impact of sleep deficiencies

among populations that experience health disparities in the U.S., including American Indians/Alaska Natives, Asian Americans, African Americans, Hispanics/Latinos, Native Hawaiians and other Pacific Islanders, sexual and gender minorities, the socioeconomically disadvantaged, and those living in underserved rural areas.