## NASEM Committee for the Assessment of NIH Research on Autoimmune Diseases

### Charge to the Committee

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### FY 2020 Congressional Interest in NIH-Sponsored Autoimmune Disease Research

- Autoimmune diseases affect ~5-7% of people in the US, and some are more common in women than in men.
- Many women are affected in their childbearing years and live with a second autoimmune illness.
- Despite the prevalence and impact of these diseases and conditions, there is no single office within NIH tasked with coordinating research across the agency or examining the complex interplay among these diseases and conditions.

# FY 2020 Congressional Mandate Addressed to NIH

- NIH to contract with NASEM to identify and review NIH's research efforts in this broad area of predominantly women's health.
- The review should explore NIH's research in autoimmune and coexisting disorders, including any barriers to such research, and the most promising areas for future research that would benefit the greatest number of patients.
- The review also should identify trends among the population suffering from these conditions, and any significant barriers to accurate diagnoses.
- Finally, the NASEM report should make recommendations for how NIH could improve and better coordinate research into these diseases and conditions, including the potential effects of establishing dedicated research entities within or external to NIH.

#### **NASEM Contract with the NIH**

- Title: Congressionally Mandated Assessment of NIH Research on Autoimmune Diseases
  - Duration: July 7, 2020 to December 31, 2022
  - NIAID tasked by the NIH OD to lead this effort
- NIH Task Leader: Ellen Goldmuntz, M.D., Ph.D.
  - Chief, Rheumatologic Autoimmune Diseases Section, DAIT, NIAID
  - Chair of the Autoimmune Diseases Coordinating Committee, NIH
- Alternate NIH Task Leader 1: Lisa Begg, Dr.P.H., R.N.
  - Senior Research Program Officer, Office of Research on Women's Health, NIH
- Alternate NIH Task Leader 2: Ms. Susan Cooper, M.Sc.
  - Director, Office of Program Planning, Operations, and Scientific Information, DAIT, NIAID

# Charge to the NASEM Committee

# Specific Tasks for the Committee to Address

- 1. Assess NIH-sponsored and other research to identify epidemiologic trends in autoimmune diseases.
- 2. For common autoimmune diseases, evaluate the NIH research portfolio with particular attention to issues such as
  - a. Risk factors
  - b. Diagnostic tools
  - c. Barriers to diagnoses
  - d. Treatment and prevention
  - e. Prospects for cures
- 3. Review NIH's research activities related to specific autoimmune diseases, the occurrence of multiple autoimmune diseases in individuals, and the interplay of autoimmune diseases and comorbidities.

# Specific Tasks for the Committee to Address

- 4. Assess trends in NIH research. Do they reflect
  - a. Changes in epidemiology
  - b. Availability of research tools and technologies
  - c. Emerging knowledge and concepts
- 5. Identify barriers to NIH-sponsored research and research gaps for autoimmune diseases.
- Identify promising areas for future NIH-sponsored research for autoimmune diseases.

# **Specific Tasks for the Committee to Address**

- 7. Evaluate Institute and Center structure in support of NIH autoimmune disease research
  - a. Are Institute programs and collaborations addressing important needs?
  - b. Are there opportunities to enhance coordination?
- 8. Produce and publish a final consensus committee report summarizing the committee's findings, conclusions, and recommendations.

## Thank you