



American Autoimmune

Related Diseases Association, Inc.

TUESDAY, NOVEMBER 18TH, 2020

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Introduction – Background Facts

- History
- AARDA
- Over 130 autoimmune diseases
- 75% women
- Some autoimmune diseases affect minorities at a higher rate
- Contributing factors-genetic, environment, infection
- Lack of awareness and research funding
- Autoimmune diseases can affect any part of the body

Autoimmune disease can affect any part of the body

Brain & Nervous System

Multiple Sclerosis
Myasthenia Gravis

Eye and Mouth

Sjögren's Syndrome
Uveitis (eye)

Thyroid

Graves' Disease
Hashimoto's Thyroiditis

Lung

Autoimmune pulmonary fibrosis
Sarcoidosis

Heart

Cardiomyopathy
Autoimmune myocarditis

Kidney

Lupus
Glomerulonephritis

Pancreas

Type one diabetes

Liver

Autoimmune liver disease
Primary biliary cirrhosis
Primary sclerosing cholangitis

Skin

Pemphigus
Scleroderma
Alopecia areata
vitiligo

Gastrointestinal

Crohn's Disease
Celiac Sprue

Joints

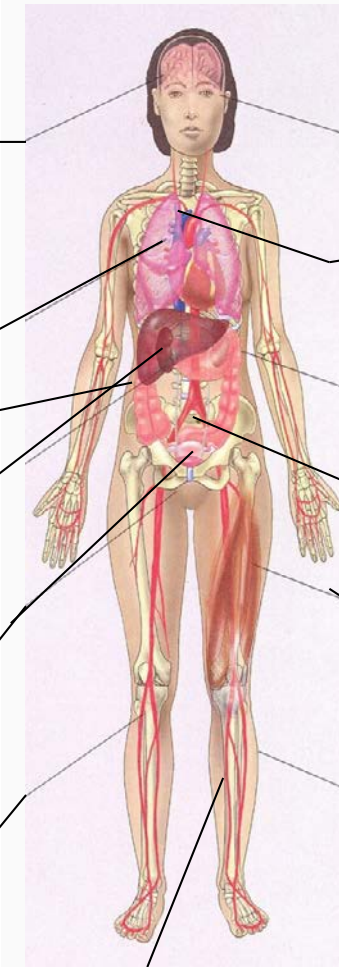
Rheumatoid Arthritis
Juvenile Arthritis

Blood

Hemolytic Anemia
Neutropenia
thrombocytopenic purpura
Antiphospholipid
Pernicious anemia

Muscles

Myositis



Major Issues

- Lack of data
- Epidemiology
- Cost of autoimmune diseases
- Lack of use of data research by older researchers
- Silos –Research, NIH, patient organizations
- Areas of research that are needed
- Future directions

Need for Increased Data

There is a significant need for current, accurate data to make informed decisions for the millions impacted by autoimmune and related diseases, including autoinflammatory diseases.



Prevalence

NIH

24 million people

23 diseases

Source-Clin Immunol Immunopathol 1997

AARDA

50 million people

153 diseases

Source –multi sources

Prevalence of Autoimmune Disease

<u>Condition</u>	<u>Source (NIH)</u>	<u>Prevalence</u>	<u>Condition</u>	<u>Source (NIH)</u>	<u>Prevalence</u>
Raynaud's Phenomenon	https://www.sciencedirect.com/science/article/pii/S0741521406013619	35,808,000	Type 1 diabetes, Juvenile diabetes	https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2925303/	1,038,666
Alopecia Areata	https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4521674/	6,414,000	Lichen Sclerosus	https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6643151/	984,600
Graves' Disease	https://www.ncbi.nlm.nih.gov/books/NBK448195/	3,972,000	CREST Syndrome	https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3666163/	955,200
Hashimoto's Thyroiditis	https://www.ncbi.nlm.nih.gov/books/NBK285557/	3,272,000	Ulcerative colitis (UC)	https://pubmed.ncbi.nlm.nih.gov/27856364/	925,035
Reactive Arthritis	https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4470267/	3,207,000	Giant Cell Arteritis, Temporal Arteritis	https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5443721/	741,228
Polymyalgia Rheumatica	https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5623160/	2,278,951	Lupus	https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6026543/	584,196
Crohn's Disease	https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5193090/	1,938,600	Multiple Sclerosis	https://www.ncbi.nlm.nih.gov/pubmed/14638958	513,477
Rheumatoid Arthritis	https://pubmed.ncbi.nlm.nih.gov/28455559/	1,788,050	Psoriasis	https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3028518/	245,852
Lyme Disease Chronic	https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6480773/	1,523,869	Uveitis	https://www.ncbi.nlm.nih.gov/books/NBK540993/	190,356
Interstitial Cystitis (IC)	https://www.ncbi.nlm.nih.gov/pubmed/9145997	1,359,660		Total	67,740,741

Why accurate and up-to-date information is crucial:

- Policy decisions
- Research decision
- Pharmaceutical industry investment
- General public awareness and understanding

Cost of Autoimmune Diseases

- In 2012, National Institutes of Allergy and Infectious Diseases (NIAID) estimated that the cost of treating autoimmune disease in the US is greater than \$100 billion annually
- There is no current estimated cost, but AARDA is funding a cost study at the Autoimmunity Institute. Study delayed due to COVID-19 pandemic

Silos

- In Research
- In Treatment
- At NIH
 - ADCC
- Pharmaceuticals

Research Areas in Need of Increased Attention

- Fatigue
- Basic
- Infection
- Antiphospholipid (APL)
- Epidemiology
- Epigenetics, Environmental triggers
- Genetics
- Microbiome- use of antibiotics early in life

Research Areas in Need of Increased Attention Cont'd

Fatigue

- AARDA's study
- Dearth of research

Basic

- Mechanism
- Triggers - environmental

Infection

- Transit
- Long term chronic illness?

Research Areas in Need of Increased Attention Cont'd

Antiphospholipid (APL)

- Multiple autoimmune diseases
- Infections
- Genetics

Epidemiology

- Nationally and Internationally

Epigenetics, Environmental Triggers

- Microbiome - use of antibiotics early in life

Genetics

Patient Needs

- Diagnosis
 - AARDA's study
 - Family history
 - Physician Education
- Coordinated treatment
- Multiple displaced treatment centers
- Autoimmune specialist
- Outreach to minority community

Research Recommendations

- Research on computational biology of biomarkers to refine diagnosis on an individual basis.
- Epidemiology studies - data will provide a defensible basis to allocate research funding for the diagnosis and treatment of the interrelated family of autoimmune diseases and allow for increased accuracy of healthcare cost forecasting.
- Research regarding the immune system and the mechanisms involved in the autoimmune response, inflammatory responses and the microbiome.
- Supporting Research Resources and Infrastructure by encouraging and supporting crosstalk among all scientific research with an emphasis on big data exchange and the field of immunology.
- Women's Health Research
- Increased basic research on the Immune system, Inflammation and the microbiome would impact on autoimmune diseases, autoinflammatory diseases, infection and cancer research.



Thank you for the opportunity to
address this committee.

QUESTIONS?