American Autoimmune Related Diseases Association, Inc.

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President

www.aarda.org
These Are The Faces of Autoimmune Disease...
The American Autoimmune Related Diseases Association is dedicated to the eradication of autoimmune diseases and the alleviation of suffering and the socioeconomic impact of autoimmunity through fostering and facilitating collaboration in the areas of education, public awareness, research, and patient services. AARDA pursues these efforts in an effective, ethical and efficient manner.
AARDA’s Programs and Services

AARDA pursues its mission with programs of:

- Patient Education
- Scientific Symposia
- Interdisciplinary Information Exchange
- Advocacy
- Public and Professional Awareness
- Autoimmune Research
Our Primary 2004 Program Objective

To assure congressional funding of the NIH Autoimmune Diseases Research Plan

Will Help:  * Early Diagnosis
            * Raise Awareness of Autoimmunity
            * Provide Coordination of Research and Treatment
            * Significant increase in autoimmune research funding
The National Institutes of Health (NIH) estimates that up to 22 million Americans are affected by autoimmune diseases, and this number includes only those diseases for which there is epidemiological studies.
Autoimmunity at a Glance

Autoimmune Disease...
- Approximately 100 diseases
- Affecting 50 million Americans
- Costing over $120 billion annually
- 250,000 new diagnoses each year
- A major cause of death in women

Autoimmune Disease by Gender

- Women 75%
- Men 25%
25 of the Most Common Autoimmune Diseases

- Graves’ disease
- Rheumatoid arthritis
- Thyroiditis/hypothyroidism
- Vitiligo
- Type 1 diabetes
- Pernicious anemia
- Multiple sclerosis
- Glomerulonephritis
- Systemic lupus erythematosus
- Sjögren’s syndrome
- Uveitis
- Scleroderma
- Addison’s
- Autoimmune hemolytic anemia
- Autoimmune hepatitis
- Goodpasture’s Syndrome
- Idiopathic thrombocytopenia purpura
- Myasthenia Gravis
- Myocarditis
- Pemphigus
- Polymyositis/dermatomyositis
- Primary biliary cirrhosis
- Rheumatic heart disease
- Relapsing polychondritis
- Psoriatic arthritis
History of Autoimmune Diseases

• Many different disciplines involved
• Lack of focus on underlying etiology
• Only disease-specific research
• Very poor cross talk among different medical disciplines
• Lack of a coordinated approach to research at NIH resulting in much duplication
• No public awareness of autoimmunity as the underlying cause of these disease
• Late diagnosis and misdiagnosis leads to disability and death
There has been a paradigm shift in our knowledge about autoimmune diseases.
Autoimmune Diseases are now known to:

- Have a common disease pathway
- Be genetically linked
Autoimmune diseases need to be recognized as a category, similar to cancer, rather than being listed under the part of the body affected by the disease.
Autoimmunity is a cause of disease. Although anatomically, autoimmune diseases are very diverse and can affect almost every organ or system in the body from the eyes and ears to the heart, liver, and skin, they are all caused by autoimmunity.
The Impact of Autoimmune Diseases

**Brain & Nervous System**
- Multiple Sclerosis

**Lungs**
- Autoimmune pulmonary fibrosis

**Kidneys**
- Lupus
- Juvenile Diabetes
- Glomerulonephritis

**Gastrointestinal**
- Crohn’s Disease
- Celiac Sprue
- Sjogren’s Syndrome

**Joints**
- Rheumatoid Arthritis

**Eye and Mouth**
- Sjogren’s Syndrome
- Uveitis (eye)

**Thyroid**
- Grave’s Disease/Hashimoto’s Thyroiditis

**Heart**
- Cardiomyopathy
- Autoimmune myocarditis

**Skin**
- Pemphigus
- Scleroderma

**Blood**
- Hemolytic Anemia
- Neutropenia
- Autoimmune thrombocytopenic purpura
- Pernicious anemia
Chronic

- Growing number of Americans with chronic illness
- Majority of patients now live a near normal life-span with most autoimmune diseases.
- However, autoimmune diseases have no cure at this time and therefore last a lifetime
- Chronic autoimmune illness is the cause of the disability
- Many have periods of flares and remissions lasting from days to months and occasionally years.
Many patients may have more than one autoimmune diseases, even as many as four or five autoimmune diseases.
Disabling Manifestations of Disease

- Extreme Fatigue
- Weight loss
- Pain
- Fever
- Crippling
- Anemia
- Neurological manifestations
- Impaired overall functioning
- Muscular weakness/atrophy
- Impaired ambulatory ability
Considerations

• Endurance is very low
• In many autoimmune diseases there are periods of flares and remission (days to months)
• Stress and overwork can cause flares
• Flares may cause additional damage
• Pacing one’s activity level is crucial to controlling many autoimmune diseases
Treatment of Autoimmune Diseases

Endocrine Autoimmune Diseases

  • Replace missing hormone such as insulin, thyroxine, etc.

Celiac Disease

  • Remove gluten from the diet
Rheumatic, Gastroenterological, Neurological, Dermatological diseases

- Reduce Inflammation by administering NSAIDS, Prednisone
- Suppress the immune system
  - Prednisone, Chemo therapeutic agents, IVIG, monoclonal antibodies (TNF)
- Continued monitoring (often requires several specialists)
- Patient Education

The patient very often has to coordinate their care and learn to live pro-actively with their illness
DIRECT HEALTH CARE COST
IN BILLIONS

SOURCES: American Cancer Society, American Heart Association, and the National Institutes of Health
NIH RESEARCH FUNDING
REPRESENTED IN BILLIONS

SOURCE: National Institutes of Health
NIH FY 2000 Autoimmune Disease Funds Research by Disease or Organ Involvement

In Millions

SOURCE: NIH
What needs to be done to prevent the suffering and societal costs of autoimmune diseases

- Increased research funding
- Education (patient, public and healthcare provider)
- Earlier diagnosis (which may prevent major organ damage)
- Identifying genetically predisposed individuals
- Coordinated approach to diagnosis and care
- Identifying triggers such as environmental factors
Tracking

• Disease Registries

• Tracking positive antibody tests at certified laboratories (Casting a wide net on autoimmune disorders and then narrowing to determine if individual autoimmune diseases are increasing.)
Metals and Autoimmunity

- Mercury
- Silver
- Gold
- Selenium
Iodine

Thyroid Dysfunction

• Graves Disease

• Hashimoto’s Thyroiditis
Organic Compounds and Autoimmunity

- Trichloroethylene (TCE)
- Polychlorinated biphenyls (PCB’s)
- Estrogenic Compounds
- Silica
Pesticides and Autoimmunity

- Serum DDE (a metabolite of DDT)
- Piperonyl butoxide (PBO)
- Malathion
Ultraviolet Radiation and Autoimmunity

- UVA/UVB
- Makes SLE worse
- May be helpful in MS and RA and Psoriasis
Stress and Autoimmunity

• May exacerbate MS, IDDM and other autoimmune diseases
• Stress affects the HPA axis
• Glucocorticoids
Recommendations for Future Directions

- Epidemiology
- Registries
- Exposures to xenobiotics
- Mechanisms
- Animal Models
Conclusion

Most of the research has focused on metal and estrogen-induced autoimmune disease. There is still much work to be done, particularly in the area of epidemiology and registries in order to understand the role of the environment in autoimmune diseases.
Thank you