

**American Autoimmune
Related Diseases Association, Inc.**

Virginia T. Ladd

President

www.aarda.org



These Are The Faces of Autoimmune Disease...





Our Mission

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.

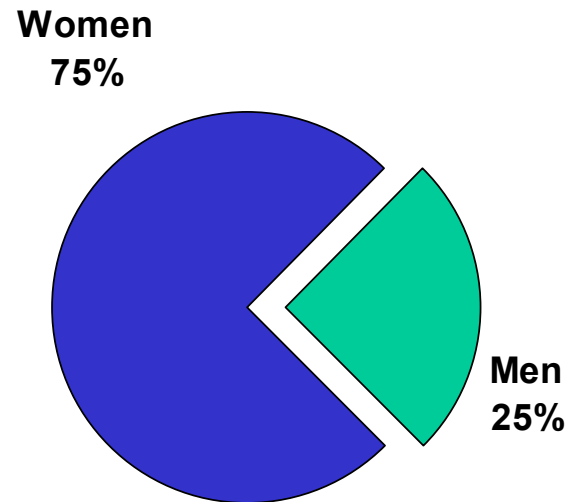


Autoimmunity at a Glance

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



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

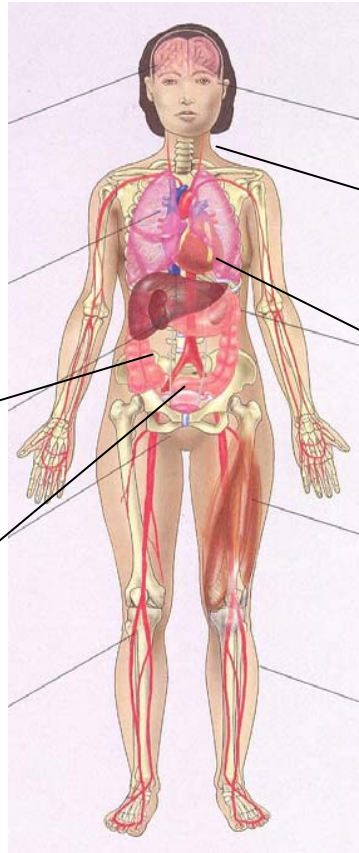
Crohn's Disease

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



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

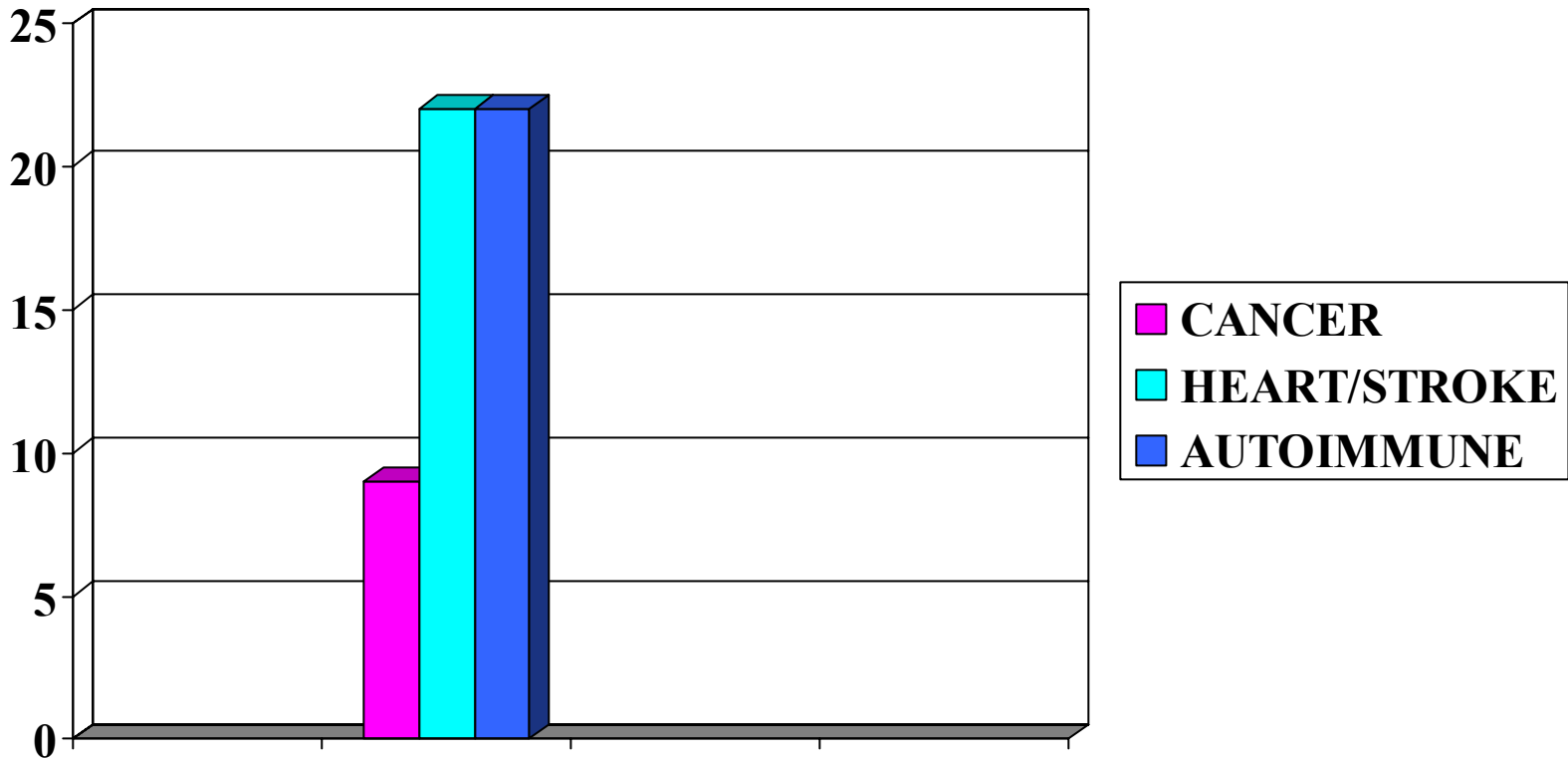
Prednisone, Chemo therapeutic agents, IVIG,
monoclonal antibodies (TNF)

- 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



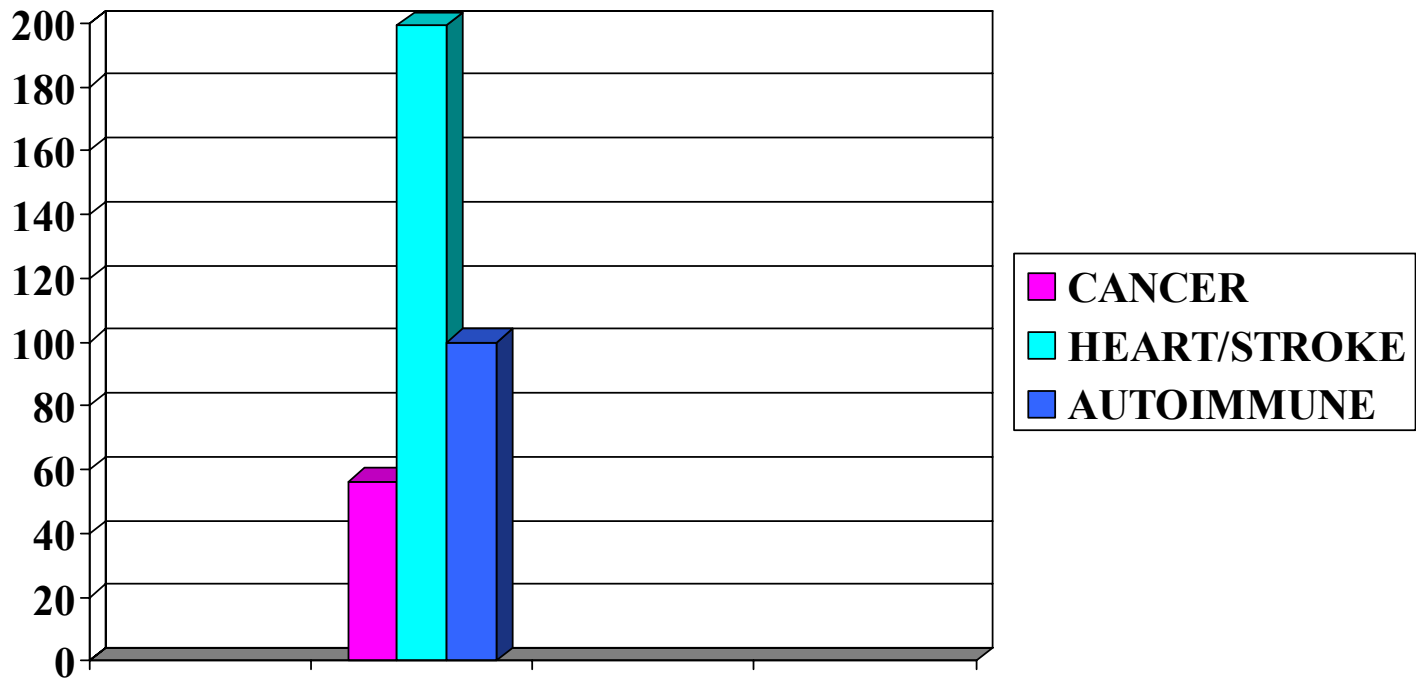
NUMBERS AFFLICTED IN USA
IN MILLIONS



SOURCE: National Institutes of Health



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

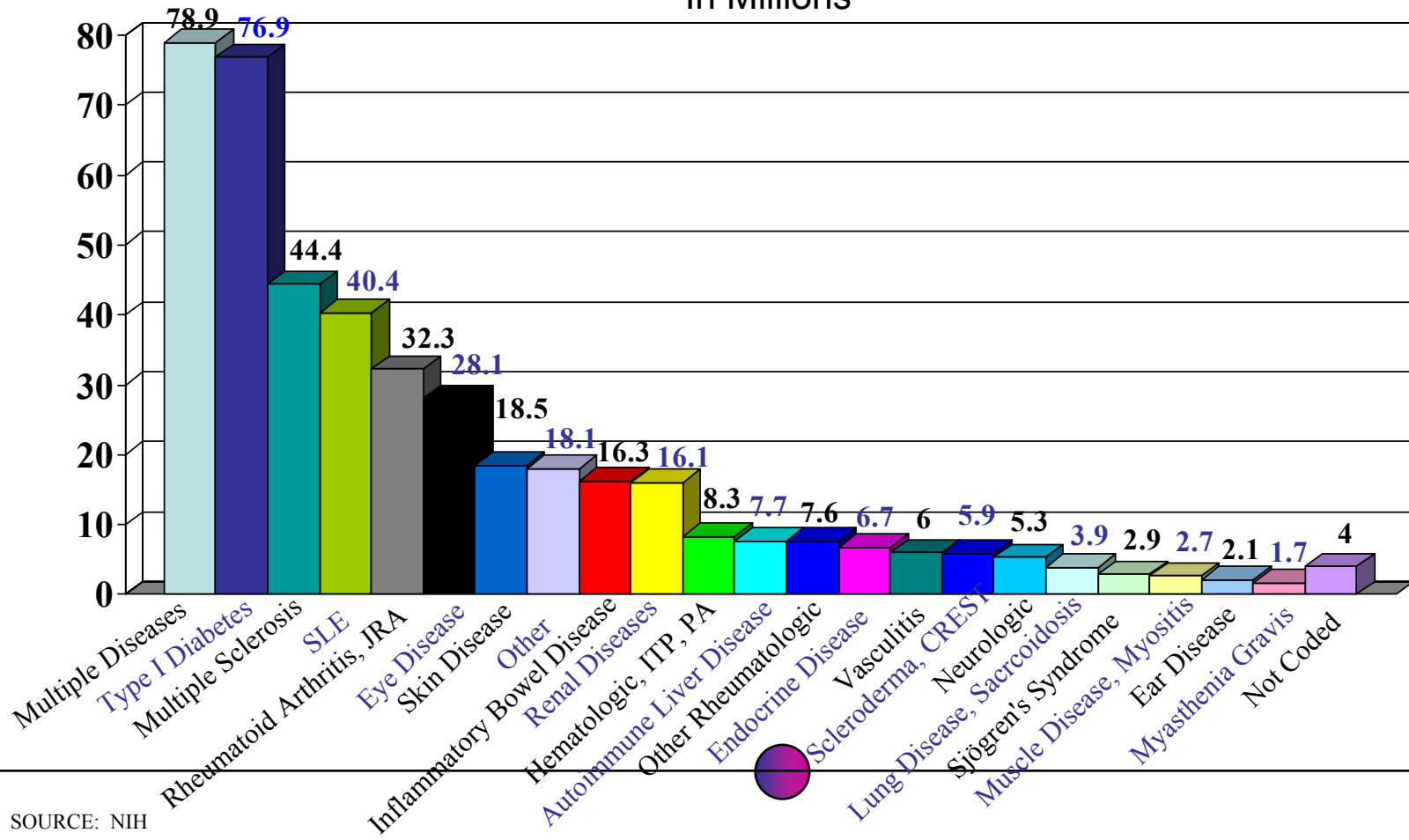


SOURCE: National Institutes of Health



NIH FY 2000 Autoimmune Disease Funds Research by Disease or Organ Involvement

In Millions



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

- Increased research funding
- Education (patient, public and health care 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

