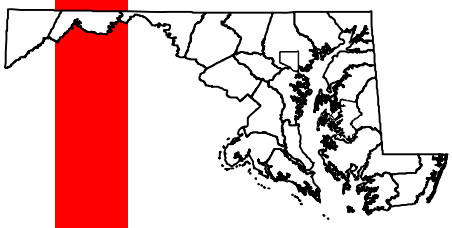
Autoimmune Disease Task Force

MARYLAND



State of Maryland
Autoimmune Disease Task Force
Final Report 2006

Established by Maryland House Bill 1494 (2005)

Governor Robert L. Ehrlich, Jr.

Lt. Governor Michael S. Steele

Secretary S. Anthony McCann
Department of Health and Mental Hygiene

Deputy Secretary Michelle Gourdine, M.D.
Public Health Services

Acknowledgements

This Maryland Task Force on Autoimmune Disease's Final Report is a product of numerous hours by countless people, and while it would be impossible to list all of the people that contributed to this report, we would like to express our sincere gratitude to a few individuals: William Eaton, MD, Johns Hopkins Hospital; The Maryland Health Services Cost Review Commission; and Chris Tkach, Ph.D, Maryland Department of Health and Mental Hygiene. Also, we would be remiss if we did not thank Secretary S. Anthony McCann, Maryland Department of Health and Mental Hygiene and Dr. Russell Moy, Director, Family Health Administration for their endless support to the Task Force over the past year.

December 2006

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MARYLAND AUTOIMMUNE DISEASE TASK FORCE

Thomas J. Liberatore, Chairperson

Dear Maryland Elected Officials:

First and foremost, thank you for affording my fellow Task Force members and myself the opportunity to serve on the Maryland Autoimmune Disease Task Force. This final report will demonstrate that autoimmune disease has a sizable impact on the citizens of Maryland, and we believe that this Task Force shows Maryland's commitment to maintaining its status as a leader in the field of public health.

The report that follows, while a completed document, represents a work in progress. We have made significant strides in just over a year; however, often times every step forward was accompanied with an increased desire to do more. As a result we end this year with a perception that we now have more to do than ever. Each success proved that those things we once thought impossible might in fact be achievable with some effort.

In the pages that follow you will begin to see the impact these diseases have on our citizens. However, the true breadth of this impact will not be conveyed in that we do not, at the present, have the full ability to measure this impact. None the less, we feel that with your support and our commitment we can begin the research that is so critical at this time. Our recommendations may seem minor compared to the size and scope of autoimmune disease on the whole, but I am confident that you they can lead to historic advancements and potential reductions in health care costs.

Thank you again for the opportunity to serve and for your leadership in public health.

With warmest regards,

Thomas J. Liberatore
Chairperson, Maryland Autoimmune Disease Task Force

Executive Summary

Autoimmune diseases are a group of poorly understood, but chronic and often disabling illnesses that affect between 14.7 and 23.5 million Americans.[1] There are autoimmune diseases that affect every part of the body and range greatly in severity. In Maryland alone it is estimated that the breadth of autoimmune diseases cost our citizens $1.87 billion annually. Acknowledging this as a significant problem, the Maryland General Assembly passed Maryland House Bill 1494 (2005), establishing the Autoimmune Disease Task Force to study the impact of autoimmune disease in Maryland. This report details the efforts and findings of the Task Force.

The Task Force was concerned with and addressed the twenty-four most common autoimmune diseases, and it choose six to highlight in depth. Those six were Rheumatoid Arthritis, Graves Disease, Type 1 Diabetes (Juvenile or Adult Onset Diabetes), Multiple Sclerosis, Systemic Lupus Erythematosus (Lupus), and Psoriasis. For each of these six diseases, the Task Force identified what the disease was, provided estimates as to its incidence, and in some cases presented possible costs of the disease.

Using these six diseases as a proxy for the entire scope of autoimmune diseases, the Task Force then addressed the specific charges of House Bill 1494 (2005). Those charges were to: discuss the costs of autoimmune diseases; identify the benefits to all Marylanders due to autoimmune disease research being conducted in Maryland; identify services available to Maryland citizens with autoimmune disease; study the level of coordination between various organizations concerned with autoimmune disease in Maryland; examine the needs of local health departments to better address autoimmune disease; consider the need for an autoimmune disease public awareness campaign; study ways to link autoimmune disease patients with services; identify ways for both the business community and schools to better serve autoimmune disease patients; examine special needs of women with autoimmune diseases; identify possible alternate public and private funding sources; and lastly, examine how current State agencies can work collaboratively with other non-State agencies to better meet the needs of Marylanders with autoimmune disease.

After carefully analyzing each of these charges the Task Force was able to recommend four specific future steps. First, for the Maryland General Assembly to create a Board of Autoimmune Disease Research to more fully study the impact of the diseases; second, for the General Assembly to provide budgetary support for support staff to the Board; third, for the Governor to proclaim a day of Autoimmune Awareness; and fourth, for the General Assembly to provide support to the Board to allow them to access the data needed to evaluate the true impact of autoimmune disease in Maryland.

[1] Autoimmune Disease Coordinating Committee, Research Plan. National Institutes of Health. 12/2002

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Tables and Figures

Background

Autoimmune diseases are a group of poorly understood, but chronic and often disabling illnesses that affect between 14.7 and 23.5 million Americans.[2] In contrast, the two most identifiable health conditions, cancer and heart disease, affect only nine million and 22 million people respectively.[3] More than 80 human diseases fall into the category of autoimmune diseases, where the immune system inappropriately activates and damages an individual's tissues and organs. These diseases can affect any organ system and have a variety of clinical manifestations. Individually, many of these diseases are relatively rare; however in aggregate, between 5 and 8 % of the population are affected by this spectrum of diseases.[4] Though autoimmune diseases are quite common, little is known about them and the people they affect. To develop a greater understanding of the epidemiology of these diseases and to create more effective public interventions, the Maryland General Assembly passed House Bill 1494 (2005), which mandates the State create a Task Force to study the impact of autoimmune disease in Maryland. The Task Force sunsets December 31, 2006.

Definitions:

Autoimmunity: A low level of auto-reactivity by the immune system is considered physiologically normal and is possibly essential to normal immune function. There are two major mechanisms known to keep autoimmunity to a low level. First, central tolerance is defined as the developmental process of terminating immature lymphocytes that happen to recognize and attack the individual. Secondly, peripheral tolerance is a series of mechanisms that exist to inactivate and suppress those self-reactive lymphocytes that manage to escape the first screening process. In those individuals where both of these safeguards fail, autoimmune diseases can develop.[5]

Autoimmune disease: A clinical syndrome caused by the activation of the immune system in the absence of infection or other discernible cause that result in tissue damage or other pathologic process. This misguided attack on the body by its own defense system often occurs in genetically susceptible individuals only after being triggered by an infectious agent or an environmental exposure.[6]

[2] Autoimmune Disease Coordinating Committee, Research Plan. National Institutes of Health. 12/2002.
[3] Ibid
[4] Ibid
[5] Johns Hopkins University School of Medicine (JHU SOM), Autoimmune Disease Research Center. 7/2006.
[6] Ibid

Types of autoimmune disease:

Modern medicine has identified over 80 different variations of autoimmune disease. There are autoimmune diseases that affect every organ of the body, and they can range greatly in severity. Some of the more common and well-known diseases are those such as Rheumatoid Arthritis, Type 1 Diabetes (Juvenile or Adult Onset), Multiple Sclerosis, and Autoimmune Thyroid; however that does not mean that the lesser-known diseases should be ignored. For example, Sjogren's Syndrome is quite common but is not as well-known. While this report will address the overall state of autoimmune disease in Maryland, it will specifically focus on six of the more common disease groups: Rheumatoid Arthritis, Graves' Disease, Type 1 Diabetes (Juvenile or Adult Onset Diabetes), Multiple Sclerosis, Systemic Lupus Erythematosus (Lupus) and Psoriasis. On the following page is a complete list of all known autoimmune diseases.[7]

[7] List comes from JHU SOM, Autoimmune Disease Research Center. 7/2006.

All Known Autoimmune Conditions:

Alopecia Areata
Ankylosing Spondylitis
Antiphospholipid Syndrome
Aplastic Anemia
Autoimmune Myocarditis
Autoimmune Addison's Disease
Autoimmune Hemolytic Anemia
Autoimmune Hepatitis
Autoimmune Hypoparathyroidism
Autoimmune Hypophysitis
Autoimmune Inner Ear Disease (autoimmune hearing loss)
Autoimmune Lymphoproliferative Syndrome
Autoimmune Myocarditis
Autoimmune Oophoritis
Autoimmune Orchitis
Autoimmune Polyendocrinopathy
Autoimmune Thrombocytopenic Purpura
Behcet's Disease
Bullous Pemphigoid
Cardiomyopathy
Celiac Sprue (CS) – Dermatitis Herpetiformis
Chronic Fatigue Immune Dysfunction Syndrome
Chronic Inflammatory Demyelinating Polyneuropathy
Churg-Strauss Syndrome
Cicatricial Pemphigoid
Cold Agglutinin Disease
CREST Syndrome.
Crohn's Disease
Degos' Disease
Dermatomyositis
Dermatomyositis - Juvenile
Discoid Lupus
Epidermolysis Bullosa Acquisita
Essential Mixed Cryoglobulinemia
Fibromyalgia – Fibromyositis
Giant Cells Arteritis
Goodpasture's Syndrome
Graves' Disease
Guillain-Barré
Hashimoto's Thyroiditis
Idiopathic Pulmonary Fibrosis
Idiopathic Thrombocytopenia Purpura
Insulin-Dependent Diabetes (Type 1 Diabetes)
Inflammatory Bowel Disease
Juvenile Arthritis
Kawasaki's Disease
Lichen planus
Lupus (Systemic Lupus Erythematosus)
Ménière's Disease
Mixed Connective Tissue Disease
Mooren's Ulcer
Multiple Sclerosis
Myasthenia Gravis
Pemphigus Vulgaris
Pemphigus Foliaceous
Pernicious Anemia
Polyarteritis Nodosa
Polychondritis
Polyglandular Autoimmune Syndrome Type 1 (PAS-1)
Polyglandular Autoimmune Syndrome Type 2 (PAS-2)
Polyglandular Autoimmune Syndrome Type 3 (PAS-3)
Polymyalgia Rheumatica
Polymyositis and Dermatomyositis
Primary Agammaglobulinemia
Primary Biliary Cirrhosis
Psoriasis
Raynaud's phenomenon
Reiter's Syndrome
Rheumatic Fever
Rheumatoid Arthritis
Sarcoidosis
Scleroderma
Sjögren's Syndrome
Stiff-man Syndrome
Takayasu Arteritis
Temporal Arteritis/Giant Cell Arteritis
Ulcerative Colitis
Uveitis
Vasculitis
Vitiligo
Vogt-Koyanagi-Harada Disease
Wegener's Granulomatosis

Burden

The burden of autoimmune disease is not only felt by the individuals who have them, but also by society in general, and range from loss of personal function to sizable economic impacts. Because of the sheer number and complexity of these diseases it remains very difficult to accurately assess these burdens. In a 1997 National Institutes of Health (NIH) study it was reported that there were only 140 published studies between 1965 and 1995 that described prevalence or burdens of various autoimmune diseases. Furthermore, only 24 of the known 80 diseases were highlighted in these studies.[8]

Due to this void in the research, the Task Force formed an agreement with the Maryland Health Services Cost Review Commission (HSCRC). This agreement granted the Task Force access to HSCRC's hospital discharge data for Maryland, which included the number of hospital discharges with the presence of an autoimmune disease. These numbers are not to be considered prevalence rates, but rather incidence rates for which a hospitalization occurred and the patient had an autoimmune disease. In the following section the report will highlight a selection of the more common, but not necessarily more prevalent, autoimmune diseases. The Maryland HSCRC data for all of the 24 most studied diseases can be found in Appendix C of this report.

Highlighted Diseases

Rheumatoid Arthritis:

Nearly 2.1 million people in the United States suffer from rheumatoid arthritis, and of those 80% have at least some loss of function.[9] Rheumatoid arthritis is a chronic autoimmune disease, mainly characterized by inflammation of the lining, or synovium, of the joints. It can lead to long-term joint damage, resulting in chronic pain, loss of function and disability. It progresses in three stages. The first stage is the swelling of the synovial lining, causing pain, warmth, stiffness, redness, and swelling around the joint. Second is the rapid division and growth of cells, which causes the synovium to thicken. Then, in the third stage, the inflamed cells release enzymes that may digest bone and cartilage. This final stage often causes the involved joint to lose its shape and alignment. This causes more pain, and a loss of movement in the joint.[10]

[8] Autoimmune Disease Coordinating Committee, Research Plan. National Institutes of Health. 12/2002.
[9] Ibid
[10] Arthritis Foundation. 2006.

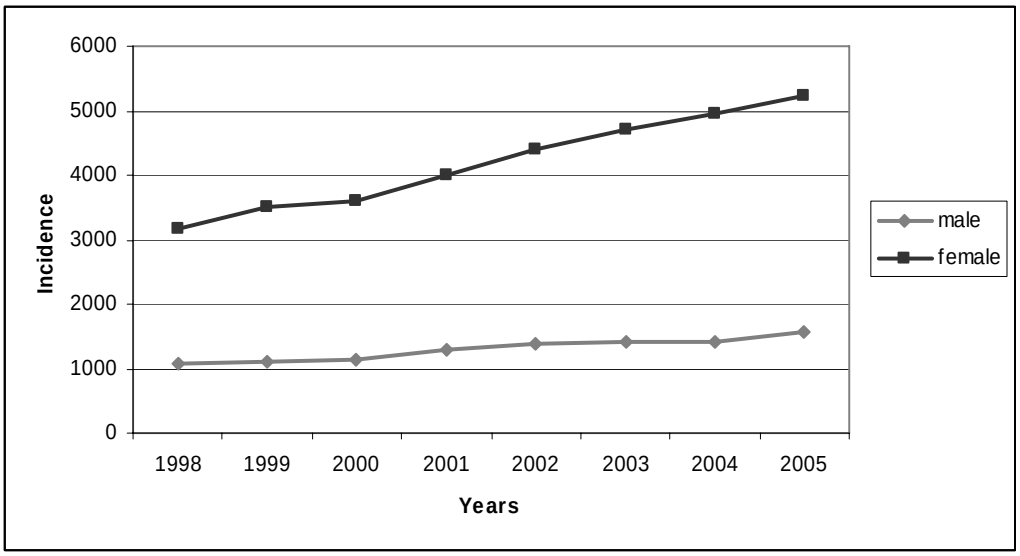
Table 1: GENDER by AGE GROUP - Maryland, 2005[11] [12]										
RHEUMATOID ARTHRITIS										
GENDER	AGE GROUP									
Frequency	05-14	15-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total
Male	*	*	27	88	230	346	384	385	106	1571
Female	*	24	134	291	658	976	1231	1392	523	5231
Total	*	28	161	379	888	1322	1615	1777	629	6802

Table 2: GENDER by RACE – Maryland, 2005[13]					
RHEUMATOID ARTHRITIS HOSPITALIZATIONS					
GENDER	RACE				
Frequency	White	Black	Other	Unknown	Total
Male	1219	313	35	*	1571
Female	3652	1425	146	*	5231
Total	4871	1738	181	12	6802

Table 3: GENDER by YEAR - Maryland, 2005[14]									
RHEUMATOID ARTHRITIS									
GENDER	YEAR								
Frequency	1998	1999	2000	2001	2002	2003	2004	2005	Total
Male	1069	1110	1150	1278	1390	1403	1409	1571	10,380
Female	3165	3501	3600	3997	4408	4720	4952	5231	33,574
Total	4234	4611	4750	5275	5798	6123	6361	6802	43,954

[11] Maryland HSCRC Hospital Discharge Database. 2005.
[12] HSCRC prohibits reporting of case numbers between 1-5 in order to preserve confidentiality. Thus, from this point forward a * in a table denotes a cell count between 1-5 cases, data having been withheld to preserve confidentiality.
[13] Ibid
[14] Maryland HSCRC Hospital Discharge Database. 1998-2005.

Figure 1: Increase in Rheumatoid Arthritis Hospitalizations [15]



Rheumatoid Arthritis Data Analysis:

In 2005 the number of women hospitalized with Rheumatoid Arthritis outnumbered their male counterparts by nearly 5:1. Women represented 77% of all Rheumatoid Arthritis hospitalizations for 2005. The bulk of the cases for women occurred after reaching the age of 45 years, and accounted for 92% of all female cases. This disease is steadily increasing; between 2000 and 2005, the number of cases increased from 3600 to 5231 for women (a 45% increase), and risen from 1150 to 1571 for men (a 37% increase).

Graves' Disease:

Graves' disease is the most common form of hyperthyroidism. It is an autoimmune disease that causes an overproduction of a thyroid hormone called thyroxin. Located in the front of the neck, the thyroid gland is an important organ that helps regulate a person's metabolic system. When thyroxin is overproduced, the body's metabolism rate can increase by 60 to 100 %; this causes a number of health problems including irregular heartbeat and insomnia.[16]

[15] Ibid
[16] Mayo Foundation for Medical Education and Research (MFMER). 7/2005.

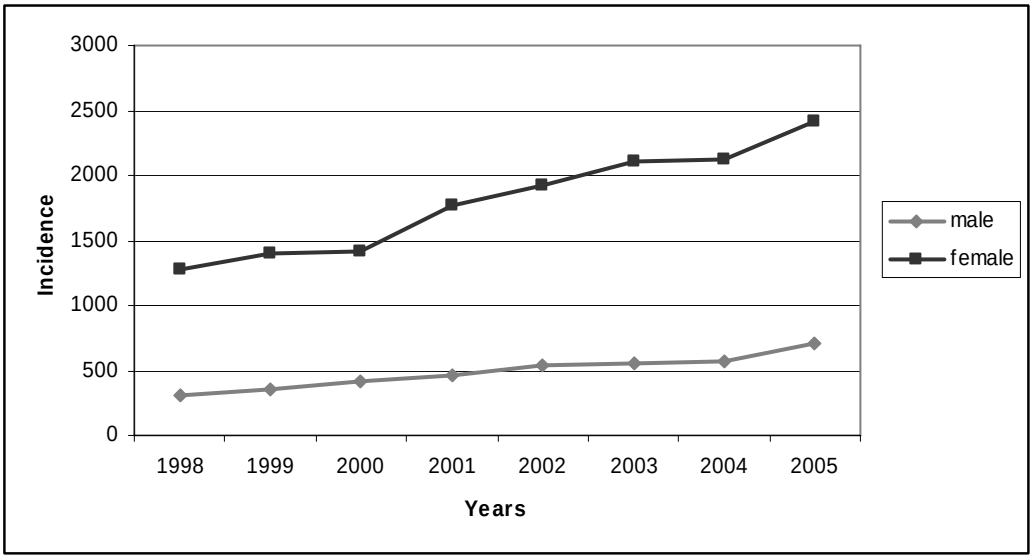
Table 4: GENDER by AGE GROUP – Maryland, 2005[17]											
THYROTOXICOSIS (Graves' Disease) HOSPITALIZATIONS											
GENDER	AGE GROUP										
Frequency	0-04	05-14	15-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total
Male	0	*	15	34	81	112	148	159	114	50	714
Female	*	6	113	255	303	358	331	342	478	234	2423
Total	*	7	128	289	384	470	479	501	592	284	3137

Table 5: GENDER by RACE – Maryland, 2005[18]					
THYROTOXICOSIS (Graves' Disease) HOSPITALIZATIONS					
GENDER	RACE				
Frequency	White	Black	Other	Unknown	Total
Male	437	250	25	*	714
Female	1333	987	101	*	2423
Total	1770	1237	126	*	3137

Table 6: GENDER by YEAR – Maryland, 2005[19]									
THYROTOXICOSIS (Graves' Disease) HOSPITALIZATIONS									
GENDER	YEAR								
Frequency	1998	1999	2000	2001	2002	2003	2004	2005	Total
Male	304	352	417	465	545	549	569	714	3915
Female	1284	1394	1420	1773	1918	2103	2130	2423	14,445
Total	1588	1746	1837	2238	2463	2652	2699	3137	18,360

[17] Maryland HSCRC Hospital Discharge Database. 2005.
[18] Ibid
[19] Maryland HSCRC Hospital Discharge Database. 1998-2005.

Figure 2: Increase of Thyrotoxicosis Hospitalizations[20]



Graves' Disease Data Analysis:

As is the case with many autoimmune diseases, 2005 data showed that Graves' Disease also disproportionately burdens women. However, while some of the autoimmune diseases are concentrated in the 35-64 age range, this disease did not seem to follow. In actuality, the 75-84 year old age group represented the largest share in comparison to all the other age groupings. Although there was a racial difference in the incidences of Graves' Disease in 2005, this difference was not as large as it was in some of the other highlighted autoimmune diseases presented here. The trend over the past eight years is noteworthy however—since 1998, the number of patients in the hospital with Graves' Disease has increased by 89% for women and 135% for men.

Type 1 Diabetes (Juvenile or Adult Onset):

Type 1 Diabetes is an autoimmune disease in which the body's own immune system attacks the beta cells in the Islets of Langerhans of the pancreas, destroying them or damaging them sufficiently to reduce or eliminate insulin production. The autoimmune attack may be triggered by reaction to an infection, for example by one of the viruses of the Coxsackie virus family. Although Type 1 Diabetes can become a very serious condition it is relatively easy to monitor and treat. Individuals with this condition are typically treated using insulin replacement therapy, carbohydrate counting, and careful monitoring of blood glucose levels using Glucose meters. Insulin delivery is also possible via an insulin pump, which allows steady infusion of insulin for prolonged periods at preset levels, and the capability to program 'push doses' (i.e. boluses) of insulin as needed at meal times. The Autoimmune Disease Coordinating Committee (AADC) with the NIH estimates that there

[20] Ibid

are between 300,000 and 500,000 cases in the United States and of those, approximately 123,000 patients are younger than 20 years old, costing an estimated $9.2 billion annually.[21]

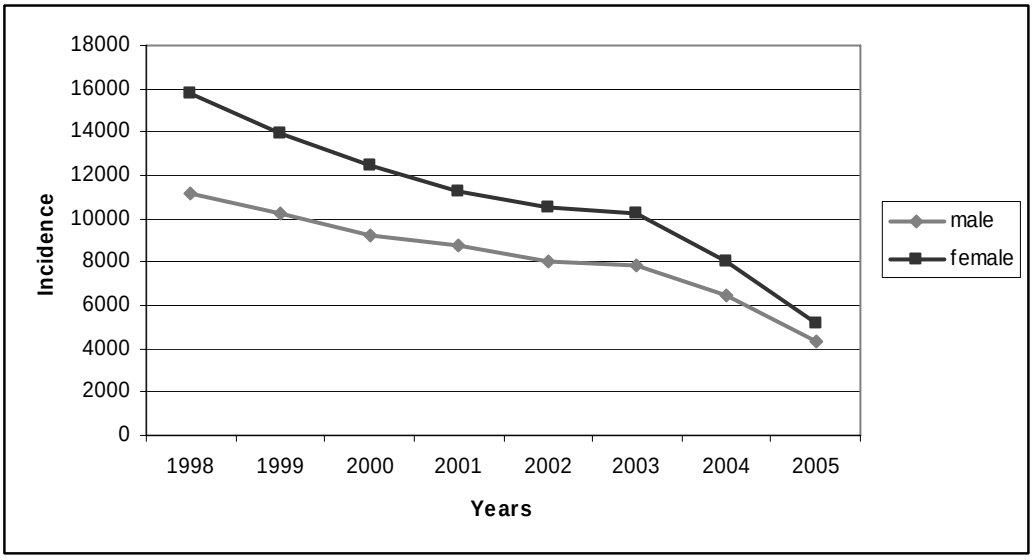
Table 7: GENDER by AGE GROUP – Maryland, 2005[22]											
TYPE 1 DIABETES HOSPITALIZATIONS											
GENDER	AGE GROUP										
Frequency	0-04	05-14	15-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total
Male	33	134	324	470	751	860	725	589	395	86	4367
Female	9	141	491	627	704	796	839	813	621	172	5213
Total	42	275	815	1097	1455	1656	1564	1402	1016	258	9580

Table 8: GENDER by RACE – Maryland, 2005[23]					
TYPE 1 DIABETES HOSPITALIZATIONS					
GENDER	RACE				
Frequency	White	Black	Other	Unknown	Total
Male	2306	1909	148	*	4367
Female	2717	2315	174	7	5213
Total	5023	4224	322	11	9580

Table 9: GENDER by YEAR[24]									
TYPE 1 DIABETES HOSPITALIZATIONS									
GENDER	YEAR								
Frequency	1998	1999	2000	2001	2002	2003	2004	2005	Total
Male	11,138	10,249	9221	8742	8001	7823	6495	4367	66,036
Female	15,802	13,939	12,482	11,275	10,556	10,238	8024	5213	87,529
Total	26,940	24,188	21,703	20,020	18,557	18,061	14,519	9580	153,565

[21] National Diabetes Information Clearing House, National Institutes of Health. 2006
[22] Maryland HSCRC Hospital Discharge Database. 2005
[23] Ibid
[24] Maryland HSCRC Hospital Discharge Database. 1998-2005.

Figure 3: Type 1 Diabetes Hospitalizations[25]



Type 1 Diabetes Data Analysis:

In 2005, there were a total of 9,580 hospitalizations in which the patient had Type 1 Diabetes. The incidence of hospitalization with mention of diabetes was fairly equally distributed between men and women (46% men and 54% women). Similarly, the frequency of mention of diabetes was equally distributed between black and white Marylanders (48% black and 52% white). Interestingly, Type 1 Diabetes is the only disease discussed in this section in which the trend is downward. Specifically, Maryland saw a 64% reduction in the number of patients hospitalized with Type 1 Diabetes. However, it should be noted that every year our medical knowledge and capabilities are being furthered and these numbers may reflect a difference in the ability to treat this disease on an outpatient basis, rather than a reduction of the disease itself. Furthermore, these tables and figures are not prevalence rates of diabetes per se, but rather, mention of the disease amongst those who have been hospitalized.

Multiple Sclerosis:

Multiple Sclerosis (MS) is a disease of the central nervous system. It can range in severity from relatively benign to completely devastating the communication between the brain and other parts of the body.

Most people experience their first symptoms between the ages of 20 and 40. The initial symptoms of MS often include blurred or double vision, red-green color distortion, or even blindness in one eye. MS commonly causes muscle weakness in the extremities, difficulty in coordination, and a lack of balance. These symptoms may be severe enough to impair walking or even standing. Most people with MS also exhibit "paresthesias,

[25] Ibid

transitory abnormal sensory feelings" such as numbness, prickling, or "pins and needles" sensations. In the worst cases, MS can leave a person partially or even completely paralyzed. Other symptoms associated with MS may also include speech impediments, tremors, dizziness, pain, and occasionally a loss of hearing. Approximately one-half of all people suffering from MS experience cognitive impairments associated with an inability to concentrate, memory lapses, poor judgment, and shortened attention spans. Depression is also a symptom commonly experienced by those suffering from MS.[26] The ADCC estimated that nearly 350,000 people suffer from MS in the United States, together creating a medical cost burden of $2.5 billion.[27]

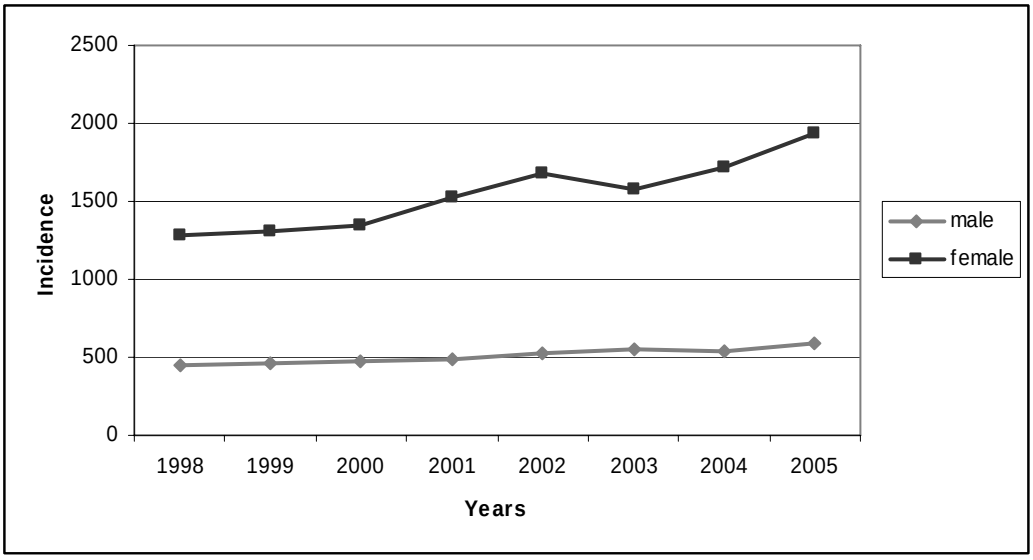
Table 10: GENDER by AGE GROUP – Maryland, 2005[28]										
MULTIPLE SCLEROSIS HOSPITALIZATIONS										
GENDER	AGE GROUP									
Frequency	05-14	15-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total
Male	*	16	28	80	171	185	84	26	*	596
Female	*	39	183	367	544	475	226	84	19	1939
Total	*	55	211	447	715	660	310	110	22	2535

Table 11: GENDER by RACE – Maryland, 2005[29]				
MULTIPLE SCLEROSIS HOSPITALIZATIONS				
GENDER	RACE			
Frequency	White	Black	Other	Total
Male	424	161	11	596
Female	1290	618	31	1939
Total	1714	779	42	2535

[26] Multiple Sclerosis Center, National Institutes of Health. 1/2006.
[27] Autoimmune Disease Coordinating Committee, Research Plan. National Institutes of Health. 12/2002.
[28] Maryland HSCRC Hospital Discharge Database. 2005.
[29] Ibid

Table 12: GENDER by YEAR - Maryland[30]									
MULTIPLE SCLEROSIS HOSPITALIZATIONS									
GENDER	YEAR								
Frequency	1998	1999	2000	2001	2002	2003	2004	2005	Total
Male	443	462	475	487	524	555	538	596	4080
Female	1277	1310	1352	1530	1679	1579	1715	1939	12,381
Total	1720	1772	1827	2017	2203	2134	2253	2535	16,461

Figure 4: Multiple Sclerosis Hospitalizations[31]



Multiple Sclerosis Data Analysis:

Multiple Sclerosis disproportionately affects women in all age groups. In 2005, 76% of the number of mentions of MS were reported by women. For both sexes, the concentration of mention of MS was for those aged 35 to 64 years. This age range accounted for 72% of all mentions of MS amongst those who were hospitalized in 2005. Also for 2005, the number of mentions of MS was greater for white Marylanders (68%, n=1714) than for black Marylanders (32%, n=779). Although the general trend of mention of MS since 1998 is rising, the rate of increase is greater for women (52%) than for men (35%).

[30] Maryland HSCRC Hospital Discharge Database. 1998-2005.
[31] Ibid

Systemic Lupus Erythematosus (Lupus):

Lupus is a chronic inflammatory disease that can affect various parts of the body, especially the skin, blood, kidneys, and joints. It is an autoimmune disease that renders the immune system incapable of distinguishing its own cells and tissues from foreign antibodies. In a healthy person, the immune system protects the body by producing antibodies that fight off foreign antigens. In a person with Lupus, the immune system produces antibodies that attack the foreign antigens, but unlike a healthy person the immune system in a person with Lupus also makes auto-antibodies that attack its own cells and tissues. The reaction between the auto-antibodies and the "self" producing immune complexes; these build up in the person's cells and tissues which causes inflammation, injury to the tissues, and pain. For most people, lupus is a mild disease affecting only a few organs. For others, Lupus may cause serious and even life-threatening problems.[32]

Table 13: GENDER by AGE GROUP – Maryland, 2005[33]

LUPUS ERYTHEMATOSUS HOSPITALIZATIONS

GENDER	AGE GROUP								
Frequency	15-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total
Male	0	0	*	7	*	8	8	0	32
Female	*	8	19	30	39	16	15	10	138
Total	*	8	23	37	44	24	23	10	170

Table 14: GENDER by RACE – Maryland, 2005[34]

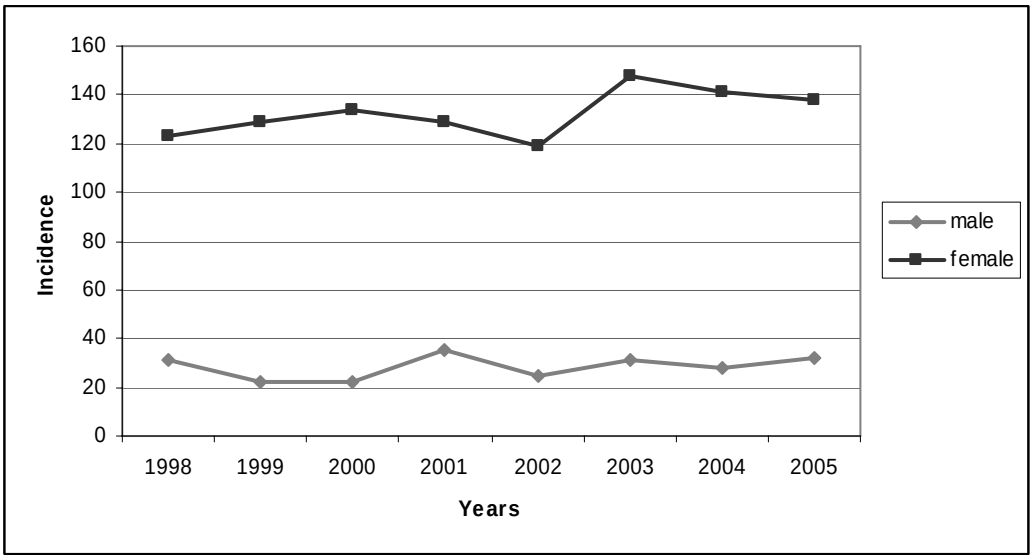
LUPUS ERYTHEMATOSUS HOSPITALIZATIONS

GENDER	RACE			
Frequency	White	Black	Other	Total
Male	18	13	*	32
Female	76	60	*	138
Total	94	73	*	170

[32] Lupus Foundation of America. 1/2006.
[33] Maryland HSCRC Hospital Discharge Database. 2005.
[34] Ibid

Table 15: GENDER by YEAR, Maryland[35]									
LUPUS ERYTHEMATOSUS HOSPITALIZATIONS									
GENDER	YEAR								
Frequency	1998	1999	2000	2001	2002	2003	2004	2005	Total
Male	31	22	22	35	25	31	28	32	226
Female	123	129	134	129	119	148	141	138	1061
Total	154	151	156	164	144	179	169	170	1287

Figure 5: Lupus Erythematosus Hospitalizations[36]



Lupus Data Analysis:

In 2005, for all age groups, Lupus was mentioned in more hospitalizations for Maryland women (81%, n=138) than for men (19%, n=32). Age appears to be an important factor for Lupus. As the table shows, mention of Lupus was rare (5%) for hospitalized persons less than 35 years of age. By contrast, race does not appear to play as significant a role in the number mentions of Lupus. In 2005, there were 94 mentions of Lupus for white Marylanders and 73 for black Marylanders. In 2002, the frequency of mention of Lupus for those hospitalized reached a low of 144 mentions; however, the following year, Maryland observed a high of 179 mentions. Since 2003, the frequency of mention of Lupus has remained steady in the 169-179 range.

[35] Maryland HSCRC Hospital Discharge Database. 1998-2005.
[36] Ibid

Psoriasis:

Psoriasis is an inflammatory skin condition that causes the body to accelerate skin cell production such that these cells mature within 3-6 days. This is unlike the normal skin cell cycle, which ranges from 28-30 days. In psoriasis-accelerated skin, cells cannot be shed properly, so they build up on the skin's surface causing visible lesions. The skin often itches, and it may crack and bleed. In severe cases, the itching and discomfort may keep a person awake at night, and the pain can make everyday tasks difficult.[37] One study estimated that between 2 and 4 % of the entire population has psoriasis and another study estimated the cost at $2 billion annually.[38]

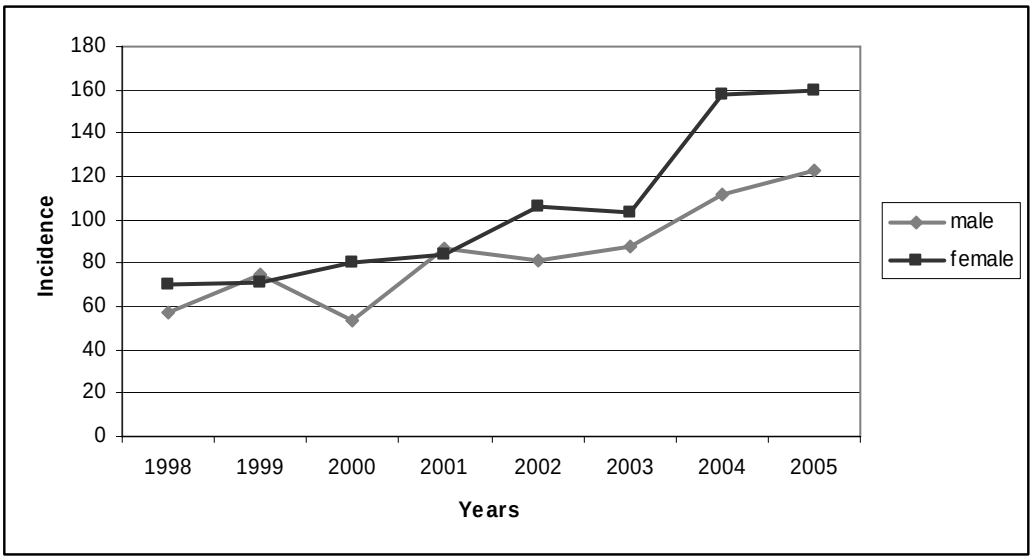
Table 16: GENDER by AGE GROUP – Maryland, 2005[39]									
PSORIATIC ARTHROPATHY (Psoriasis) HOSPITALIZATIONS									
GENDER	AGE GROUP								
Frequency	05-14	25-34	35-44	45-54	55-64	65-74	75-84	85+	Total
Male	*	*	12	28	29	25	19	7	123
Female	0	*	22	24	66	17	24	*	160
Total	*	*	34	52	95	42	43	7	283

Table 17: GENDER by RACE – Maryland, 2005[40]					
PSORIATIC ARTHROPATHY (Psoriasis) HOSPITALIZATIONS					
GENDER	RACE				
Frequency	White	Black	Other	Unknown	Total
Male	106	11	*	0	123
Female	141	14	*	*	160
Total	247	25	10	*	283

[37] American Academy of Dermatology, PsoriasisNet. 8/2005.
[38] Autoimmune Disease Coordinating Committee, Research Plan. National Institutes of Health. 12/2002
[39] Maryland HSCRC Hospital Discharge Database. 2005.
[40] Ibid

Table 18: GENDER by YEAR – Maryland, 2005[41]									
PSORIATIC ARTHROPATHY (Psoriasis) HOSPITALIZATIONS									
GENDER	YEAR								
Frequency	1998	1999	2000	2001	2002	2003	2004	2005	Total
Male	57	75	54	87	81	88	112	123	677
Female	70	71	80	84	106	103	158	160	832
Total	127	146	134	171	187	191	270	283	1509

Figure 6: Psoriatic Arthropathy Hospitalizations[42]



Psoriasis Data Analysis:

In 2005, a mention of psoriasis-related hospitalizations was greater for Maryland women (57%, n=160) than for men (43%, n=123). Age appears to play a significant role in psoriasis. Of the 283 mentions of psoriasis in 2005, only six were for persons under the age of 35 years. Over one-half (63%) of the mentions of psoriasis were observed in persons between 35-64 years of age. In the same year, white Marylanders accounted for an astounding 87% of all psoriasis mentions. In each year since 1998, the frequency of psoriasis mentions amongst those who have been hospitalized has increased in Maryland. The 283 mentions in 2005 represent a 122% increase in psoriasis mentions over the past 8 years.

[41] Maryland HSCRC Hospital Discharge Database. 1998-2005.
[42] Ibid

Charges of the Legislation

Charge I: Identify the costs of autoimmune disease that have been incurred by the State and study potential ways to reduce the cost.

Due to various limitations, it is difficult to extract a State-level cost of autoimmune disease. However, this does not mean cost estimates are completely unattainable. In a presentation at the NIH, it was reported that the United States observes a direct annual health care cost due to treatment of autoimmune diseases in the range of $100 billion.[43] Based on that figure a direct health care cost per capita can be calculated for the United States. Using that per capita estimate, one could then impose that number on Maryland's population and create a general approximation of the direct health care cost estimate for the State of Maryland:

- ➔ *$100 Billion / 300 million Americans = $333.33 national per capita*[44]
- ➔ *$333.33 per capita expenditure X 5.6 million Marylanders = $1.87 billion*[45]

While this $1.87 billion estimate may seem staggeringly high, it includes only the direct health care cost, and does not take into consideration the cost of lost economic productivity, family disturbance, emotional suffering, or any other cost incurred by sickness.

The most promising method to reduce this cost would be through the use of research. The cost of autoimmune diseases is high is in part because their complexity is not fully understood. Through research, some of this complexity can be shed, and thus the diseases' incidence decreased.

Charge II: Identify benefits to the citizens of Maryland due to research and medical work conducted in Maryland on autoimmune disease and study ways to improve the benefits to the public and the professional health community.

As previously stated, research is the most promising vehicle towards effectively treating and curing autoimmune diseases. There are many benefits that the citizens and health professionals from Maryland would gain from becoming the epicenter for advanced research on autoimmune diseases. Citizens would benefit by living in the same State as the ground-breaking research centers, which in turn would allow them easy access to the latest diagnoses and treatment techniques. Professionals would benefit from their direct

[43] Autoimmune Disease Coordinating Committee, Research Plan. National Institutes of Health. 12/2002
[44] Population estimate taken from US Census Bureau. 10/2006.
[45] Ibid

participation in these groundbreaking discoveries and advances. Maryland citizens have benefited for years from living in a State that is considered the leader in many areas of public health and medicine, and this benefit will be enhanced by advancing autoimmune disease research and treatment.

Charge III: Identify the services available in the State for people with autoimmune diseases and the gap in services, including duplication and fragmentation.

The State of Maryland is fortunate to have many different organizations working to solve the challenges of autoimmune disease. The services are not just limited to hospitals and nursing homes, but include major research institutions, home-based care centers, and a multitude of support organizations. Often however, there is a great amount of duplication and fragmentation of services. The list below shows where some of the services currently are housed; however the list is not exhaustive.

University Setting:

Johns Hopkins Medical Center: The John Hopkins Autoimmune Disease Research Center offers leadership in the study and development of improved diagnosis, treatment, and prevention of autoimmune diseases. The Autoimmune Disease Research Center includes:[46]

- The Multiple Sclerosis Center
- The Kelly G. Ripken Program for individuals with disease of the thyroid
- The Autoimmune Skin Diseases Center
- The Johns Hopkins Diabetes Center
- The Johns Hopkins Division on Rheumatology
- The Chronic Pain Treatment Program at Johns Hopkins

University of Maryland: The University of Maryland has numerous centers dedicated to autoimmune disease. These include:[47]

- The Center for Celiac Research
- The Joslin Diabetes Center
- The Myasthenia Gravis Center
- The Maryland Center for Multiple Sclerosis

[46] Johns Hopkins University School of Medicine
[47] University of Maryland, School of Medicine

Local Support Groups and Disease Associations:[48]

American Diabetes Association, Maryland Chapter:

- Reisterstown, MD (Central Office)
- Columbia, MD
- Towson, MD

The American Pain Foundation:

- Montgomery County
- Prince George's County
- Anne Arundel County
- Howard County
- Baltimore City

Arthritis Foundation, Maryland Chapter:

- Owings Mills, MD (Central Office)
- Southern Maryland Branch
- Western Maryland
- Metropolitan Washington Chapter

Lupus Mid-Atlantic:

- Bel Air

The Maryland Celiac Sprue Association:

- Brookville, MD
- Westminster, MD
- Timonium, MD
- Cockeysville, MD

The National Multiple Sclerosis Society, Maryland Chapter:

- Owings Mills (Central Office)
- Eastern Shore Regional Office

Scleroderma Society, Maryland Chapter:

- Greater Washington, D.C.

Sjopgren's Syndrome Foundation, Maryland Chapter:

- Bel Air Methodist Church
- Bethesda, MD (Foundation National Office)
- Bethesda, MD, National Institutes of Health

[48] Further contact information located in the appendix

Charge IV: Study the level of coordination or lack of coordination among State agencies, State health services, and private health services.

Because of the number, nature, and complexity of autoimmune diseases, it is difficult to specifically identify coordinated efforts. In addition to the university and private organizations mentioned in Charge III, there exist State-level coalitions that address autoimmune diseases. Some of these coalitions do not address a specific disease, but rather issues of healthy diet and physical activity, which have been proven effective in the management of these diseases. Some of these groups include, but are not limited to:

- The State Diabetes Coalition;
- The State's Nutrition and Physical Activity Coalition;
- Healthy Eating Active Lifestyles Coalition;
- Health Choices Coalition (AHA, ACA, ADA); and
- Maryland Healthy Schools Coalition

At this point there is no centralized group that is charged with bringing together all the independent groups (State level, private and university). Further, there are often high levels of duplication among these groups, in that numerous members of these coalitions sit with many different groups. A central 'clearinghouse' would go a long way in creating a more partnership oriented approach, which will eventually lead to decreased duplication. There is no question that coordinated research is critical.

Charge V: Identify the need for training on autoimmune disease for State and local health departments and explore collaboration with State universities and the National Institutes of Health to implement such training.

Training can and should occur at all levels in the continuum of care. At this time, however, the creation of a multi-layered training program may be a bit premature. As stated, there is a sizable void in autoimmune research and as a result it is difficult to provide training in prevention, diagnosis, and treatment for some of the more common State would thus be more suited at this time to seek further research, not training. Any training that does occur should be directed at the decision makers to help them understand the critical need for further research in this field.

Given the investment in research and the multitude of professionals at both the State's premiere universities, as well as the NIH, these institutions could serve as a useful resource in training the appropriate people within the State.

Charge VI: Identify ways for the local health departments to integrate the most advanced autoimmune disease diagnostic techniques and treatments into their health services.

As previously mentioned, Maryland is fortunate to have access to the professionals at both the State's major medical universities and the NIH. These resources have the potential to offer significant breakthroughs in autoimmune disease treatment and diagnosis. However, it must be noted that training local health departments to provide any newly identified methods of autoimmune disease treatment and diagnosis may be misguided. The fundamental purpose of the local health departments is not treatment, but rather the overall advancement of public health.

What is possible is that these professionals provide train-the-trainer programs that help local health department personnel assist individuals with autoimmune diseases to find the care they need, link them with the appropriate support groups, and provide overall education, all of which may best be realized through expanded research. While such relationships cannot be created without cost, it is conceivable that the cost would be minimal. However, that is contingent on NIH's willingness to partner with Maryland as well as the availability of their professionals.

Charge VII: Identify the need of a public awareness campaign on autoimmune disease in the State to encourage early diagnosis and treatment to lower the cost of autoimmune disease, and explore ways that such a campaign could be funded and implemented.

Throughout this report the need for research has been highlighted. It must also be mentioned that the dissemination of the knowledge that comes from that research must be marketed as effectively as possible. As advancements are made, the general public and autoimmune disease community need to be kept abreast of advancements in order that these developments are as beneficial as possible and reach those populations who would best be served by the findings.

Along with the dissemination of the research findings, a general public awareness campaign about what autoimmunity is and how many people it affects should be implemented. This campaign should include public service announcements and the creation of multi-language brochures on the various autoimmune diseases for public distribution.

Charge VIII: Identify ways to link autoimmune patients with health services in the State.

The above-mentioned public awareness campaign could also be used to reach those Marylanders who have been previously diagnosed, but are unaware of the autoimmune disease services available to them. This campaign could include information on all the services offered by the various institutions and organizations cited above.

Another opportunity for linkage is through the use of the train-the-trainer programs. Identified personnel at local health departments could become the official local contact who is fully knowledgeable of all the autoimmune disease services available to that community. These people could be trained by the same people who are conducting research in the State, and consequently could be viewed as experts in the area. While again this program could not be implemented without cost, it may in fact be achieved with minimal spending. Further investigation would be necessary to determine these costs more precisely however.

Charge IX: Identify collaborations with the business community and employers on the long-term and chronic effects of autoimmune disease and ways to assist employees affected by autoimmune disease.

The existing Americans with Disabilities Act (ADA) is a foundation to ensure individuals with autoimmune disease have a conducive work environment.[49] The difficulty is often that these individuals do not appear to be sick. Often autoimmune disease can be an 'invisible disease' with no outward signs of sickness, with only the individual knowing about their condition. While there may not be any outward signs of illness, individuals with autoimmune disease do suffer. However, the ADA alone may not address the needs of a patient with little or no visible symptoms.

Increased research as to what seems to cause disease 'flare-ups' as well as awareness about autoimmune diseases would help employers better understand how they can create a work environment that not only maximizes the employees productivity, but also minimizes their risk of becoming sick.

Charge X: Identify the special needs of women with autoimmune disease and ways to assist them.

For reasons still not fully understood, women are much more susceptible to autoimmune disease than men. Women account for almost 75% of all autoimmune disease

[49] Information and Technical Assistance with the Americans with Disabilities Act. 10/2006.

cases in the United States.[50] These trends are echoed in the HSCRC data that have been provided for the selected diseases in this report and for all the diseases listed in Appendix C. The reason for this is not known. Again this underscores the need for further investigation and research.

It also seems to be a certain age group among the female population (child-bearing age), but again it is not known why. Due to this phenomenon, women often need special consideration with regard to child care and emotional support. This can be an especially challenging time in a woman's life, and she may need various levels of support.

Charge XI: Identify the special needs of Students with autoimmune disease.

Just as with women, special consideration needs to be given to students with autoimmune disease. Some of these diseases can slow the cognitive process, thus requiring students to need more time in test-taking, or causing them to become physically disabled, requiring a longer time to get to and from class.[51] Also, as with women this can be an emotional challenge, therefore a readily available supply of functioning peer support groups should be a priority. Fragmentation and duplication can be identified, and the movement or creation of support groups can be made as needed to ensure all geographic areas within the State are served. A study of this group can also benefit all other sub-populations with autoimmune disease.

Charge XII: Identify private and public funding resources to support future planning and implementation of the Task Force recommendations.

Funding is needed to further investigate and promote recommendations. The problems associated with the high rates of autoimmune disease are far too complex to be solved without financial and legislative support. Funding should be sought from a variety of sources, including the State, related national autoimmune organizations, and the private sector. For example, pharmaceutical companies that are dedicated to finding prescription drug solutions for many of the autoimmune diseases may be willing to help sponsor State-run initiatives. These companies increase profits by creating a larger customer base. Sponsorship of State-run public awareness campaigns and research efforts provide a tremendous opportunity for name recognition. For example, the National Autoimmune Disease 2006 Conference in Washington, D.C. was sponsored by La Jolla Pharmaceutical Company, which is highly invested in the creation of a Lupus drug. Some other potential funding outlets could be insurance providers, hospitals, or primary level care providers.

[50] Autoimmune Disease Coordinating Committee, Research Plan. National Institutes of Health. 12/2002.
[51] Ibid

Charge XIII: Identify ways for the State to work collaboratively with existing private resources in the State, such as autoimmune disease patient groups, professional health associations, health maintenance organizations, hospitals, and the medical research and biotechnology research communities.

Partnerships could prove to be the single most important piece of success, provided funding is available. The State should actively pursue partnerships with its autoimmune disease stakeholders. The level of research that is needed at this time is far too great a task for a State health department alone. There must be a means to bring everyone together under one common goal, or success will continue to be elusive. As the State has done successfully in many other areas of public health, the Task Force recommends the development of an Autoimmune Disease Coordinating Office. At this point it would be dangerous to estimate an associated cost with this strategy. The unknown variables are far too many in number and any estimate of cost would contain a range so large that would not be valuable. However, it can be assumed that the cost would not be minimal.

Recommendations

A Work in Progress:

The Maryland Autoimmune Disease Task Force has come a long way in just one year; however, there remains a great deal left to do. Through our successes, the Task Force has come to realize that our capacity to address the concerns of autoimmune disease patients may very well be larger than originally anticipated. Strides can be made in decreasing the estimated $1.87 billion cost Maryland incurs every year due to autoimmune disease with a relatively small investment. With financial support, the State can be the leader in the autoimmune disease community as it already has the infrastructure, the motivation, and the people. It is the recommendation of this Task Force that the following be initiated:

1) The Maryland General Assembly create a Board of Autoimmune Disease Research that is to be in existence for a period of four (4) years, to sunset December 31, 2011.

2) The Maryland General Assembly provide budgetary support to that Board to hire one (1) full-time State employee as well as budgetary support to sponsor needed research and a public awareness campaign.

3) The Governor proclaim a day of Autoimmune Disease Awareness that is to be an annual event by which the Board kicks off its public awareness campaign.

4) The Maryland General Assembly provide support for the Task Force to have access to State databases in order to obtain data needed to achieve its research goals.

The members of the Task Force feel confident that with this support Maryland can and will become a leader in yet other area of public health.

Appendix

Appendix A: Task Force Membership

Thomas J. Liberatore, Chair
Representing an advocacy group associated with mental health issues due to autoimmune disease

The Honorable Gwendolyn T. Britt
Maryland State Senate, District 47, Prince George's County

The Honorable Marilyn R. Goldwater, R.N., F.A.A.N.
The Maryland House of Delegates, District 16, Montgomery County

Coleen Bertsch
Representing a health care provider with knowledge about autoimmune disease

Patricia E. Boehm, R.N., M.S., C.N.A.
The Center for Preventive Health Services, Maryland Department of Health and Mental Hygiene

Yvette Colon, MSW, ACSW, BCD
Representing American Pain Foundation, a patient advocacy organization for pain associated with autoimmune disease

Lori Freeman
Representing consumers of autoimmune disease services

Deborah M. Forish
Representing family members or care takers of people with an autoimmune disease

Reinaldo A. John
Representing family members or care takers of people with an autoimmune disease

Joan J. Manny
Retired Nurse, autoimmune disease patient advocate

Noel R. Rose, Ph.D, M.D.
Representing States universities that conduct research about autoimmune disease

Hal Sommers
Vital Statistics Administration, Maryland Department of Health and Mental Hygiene

Robert J. Sweeny
Maryland Department of Disabilities

Brenda A. Wilson
Maryland Insurance Administration

Appendix B: Complete List of Autoimmune Disease Organizations

The Maryland Celiac Sprue Association:
Regional Contact:
Baltimore, Maryland
Cathy Hall
410-461-0684

Regional Contact (Cel-Kids Network):
Baltimore, Maryland
Jeanne Simkins
410-683-3391

The Maryland Pain Initiative:
1-888-615-PAIN
Regional Office:
Baltimore City
201 N. Charles St. Suite 710
Baltimore, Maryland

The American Pain Foundation:
Local Support Groups:

1. Montgomery County
   Davis Library
   6400 Democracy Blvd.
   Bethesda, Maryland
2. Prince George's County
   9885 Greenbelt Rd.
   Lanham, Maryland
3. Anne Arundel County
   West County Library, 1325
   Annapolis Rd.
   Odenton, Maryland
4. Howard County
   8840 Stanford Blvd., Suite 4300
   Columbia, Maryland

The National Multiple Sclerosis Society, Maryland Chapter:
Local Support Groups:

1. Baltimore County
   11403 Cronhill Drive, Suite E
   Owings Mills, Maryland 21117
   443-641-1200
   1-800-FIGHT MS
2. Worcester County

   Eastern Shore Office
   104-A Williamsport Circle
   Salisbury, MD 21804

Scleroderma Society, Maryland Chapter:
Local Support Groups:
Baltimore County
Towson Library
320 York Road
Towson, Maryland
Lori Freeman
410-802-4291

Scleroderma Foundation, Greater Washington, D.C. Chapter:
Regional Contact:
Washington D.C Chapter
2010 Corporate Ridge, 7th Floor, PMB #126
McLean, VA 22102

American Diabetes Association, Maryland Chapter:
Regional Contact:
Baltimore County
American Diabetes Association Maryland Affiliate Inc.
Central Avenue Reisterstown, Maryland 21136
410-526-4995
800-232-3662
National Contact:
Detroit, Michigan
22100 Gratiot Ave.

East Detroit, MI 48021
586-779-3900

Maryland Association of Diabetic Educators:
Regional Contact:
Howard County
Guilford Road, #223
Columbia, MD 21046

Juvenile Diabetes Chapter:
Regional Contact:
Baltimore County
200 E. Joppa Road, Suite 105,
Towson, MD 21286
410-823-0073

Maryland Diabetes Prevention and Control Program:
Regional Contact:
Baltimore City
Family Health Administration
201 West Preston Street, 3rd Floor
Baltimore, Maryland 21201
410-767-5300

Arthritis Foundation, Maryland Chapter:
Local Support Groups:

1. Baltimore County
   Maryland Chapter
   9505 Reisterstown Road, Suite 1
   North Owings Mills, Maryland 21117
   410-654-6570
2. Anne Arundel County
   Southern Maryland Branch
   714 B & A Boulevard
   Severna Park, Maryland 21146
   410-544-5433
3. Western Maryland Branch
   22 South Market Street
   Frederick, Maryland 21701
   301-663-0303

Regional Contact:
Prince George's County and Montgomery County
Metropolitan Washington Chapter
2011 Pennsylvania Avenue, NW
6th Floor Washington, DC 20006
202-537-6800

Lupus Mid-Atlantic:
Regional Contact:
Baltimore County
Lupus Mid-Atlantic
7400 York Rd., Suite 308
Baltimore, Maryland

Sjogern's Syndrome Foundation, Maryland Chapter:
Local Support Groups:

1. Harford County
   Bel Air Methodist Church
   410-836-1040
2. Charles County
   LaPlata Library
   301-843-2197
3. Metropolitan Washington area
   301-530-4420

Wegener's Granulomatosis Association, Maryland Chapter:
Local Contact:
Baltimore City
Hellmann, David., M.A.C.P.
Johns Hopkins Bayview Medical Center
410-550-0516

National Eczema Society:
National Contact:
California:
National Eczema Association
4460 Redwood Hwy., Ste. 16-D
San Rafael, CA 94903-1953
415.499.3474
800.818.7546

Myasthenia Gravis Foundation:
Maryland/D.C./Delaware Chapter:
P.O. Box 186

Pasadena, Maryland 21123
866-437-6193
410-432-6193
Local Support Groups:

1. Bethesda, Maryland
   Bill Delorenzo
   301-384-1229
2. Western Maryland
   Dave Miller
   717-597-5107

Alopecia Areata Foundation:
National Office:
1233 20th Street, NW, Suite 402
Washington, D.C. 20036
202-887-0082

Platelet Disorder Support Association:
Local Support Group:
Montgomery County
133 Rollins Ave. Suite 5
Rockville, Maryland 20852
877-528-3538
301-770-6636

Maryland Autoimmune Disease Statistics for Select Autoimmune Diseases[52, 53]

This section is intended to supplement the 'Highlighted Diseases' section of the report and contains data for the 24 most commonly studied autoimmune diseases. The data is derived from analysis of the Maryland Hospital Services Cost Review Commission Hospital Discharge Database. All tables and figures that follow are products of that data. The numbers reported are not to be understood as prevalence numbers, but rather incidences of hospitalizations in Maryland for the said year by which the patient had the given autoimmune disease.

[52] All data in the following section comes from analysis of the Maryland HSCRC Hospital Discharge Database.

[53] For all charts in this section a * denotes cell count is less than 6 records. Data were excluded to preserve confidentiality