

dataMSA Surveys for Multiple System Atrophy



Patient Data Reports
Updated: 2014 - 2019

Bill Sydnor

Datamsa Multiple System Atrophy Patient

Jeffrey T. Walburn, Charles Frank Ide

A red circular graphic with a gradient, appearing as a partial circle or a stylized 'C' shape, located to the right of the authors' names.

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Datamsa Multiple System Atrophy Patient Data Report Bill Sydnor, 2015-12-02 Multiple System Atrophy MSA is a rare degenerative progressive neurological disease so named because its signs and symptoms affect multiple systems of the body. There is no effective treatment and no cure. Because of its rarity, the experiences of MSA patients are seldom heard. With the input of fellow patients and individuals affected by MSA, caregivers loved ones of those lost, I developed a survey to assess our collective experiences. Several drafts of the survey were developed, reviewed, adjusted, and edited over a period of months. In March 2014, I launched dataMSA in recognition of MSA Awareness Month, March. The dataMSA survey was open to all who may have been affected by the disease, patients, caregivers, and loved ones speaking for those lost to MSA. At the time of this printing, nearly 350 people from across the globe have added their experiences to the dataMSA collection. The purpose of this collection is to raise the voices of MSA patients to advance research and education to enhance treatment and to find a cure for this debilitating disease. 100% of the profits from the sale of this book will be donated to the MSA Coalition. **Datamsa**

Surveys for Multiple System Atrophy Bill Sydnor, 2015-12-07 When I couldn't find patient-driven information about MSA and when my doctors didn't have a lot of information about patient experiences, I set out to create a way patients could share their experiences. dataMSA has collected information from nearly 350 persons worldwide who have been affected by MSA, patients, caregivers, loved ones, to those lost. The data has been shared with researchers at UCSF, Vanderbilt, Mayo Clinic, UF, and other centers. This text is an invaluable resource for health care providers, support staff members, and others who seek information about multiple system atrophy. No revenue is collected from the surveys, and patients remain confidential. 100% of the profits from this book will be donated to the MSA Coalition to support research for a cure. Thank you for helping us raise our MSA voices. Bill Sydnor, dataMSA creator. **Multiple System Atrophy** Gregor K. Wenning, Alessandra

Fanciulli, 2013-09-14 This textbook provides a comprehensive monography on multiple system atrophy. MSA, a rare and fatal neurodegenerative disorder, that presents with autonomic failure and either parkinsonism (MSA-P) or cerebellar ataxia (MSA-C). The underlying neuropathology of MSA is characterized by striatonigral degeneration (SND), olivopontocerebellar atrophy (OPCA), and unique oligodendroglial cytoplasmic alpha-synuclein inclusions. MSA is therefore classified among the alpha-synucleinopathies such as Parkinson's disease, pure autonomic failure, and dementia with Lewy bodies. Over the last decade, there have been important advances in early diagnosis, pathogenesis research, and clinical trial activity. The monography will cover the entire spectrum, ranging from molecular and genetic work to symptomatic and interventional therapies. The book is written for movement disorder clinicians and basic neuroscientists interested in degenerative movement disorders.

Autonomic Nervous System Gregor K. Wenning, Florian Krismer, 2013-11-11 Multiple system atrophy (MSA) is a sporadic and fatal synuclein-linked oligodendroglionopathy manifesting with progressive autonomic failure, poorly levodopa-responsive parkinsonism, and cerebellar ataxia in any combination. Here, we review key aspects of MSA, integrating important insights

from rapidly emerging fields such as genetics diagnostic work up including imaging and translational therapies aimed at disease modification

Understanding Multiple System Atrophy (Msa) Dr Gideon Hyde, 2025-06-25 Are you struggling to understand the difference between MSA and Parkinson's disease Do you feel overwhelmed by a recent MSA diagnosis in your life or a loved one's Are you looking for practical tools to manage MSA symptoms day by day Do you want to catch the early signs of MSA before it progresses further Are you in need of clear answers emotional guidance and reliable care strategies Understanding Multiple System Atrophy MSA is your essential guide to navigating one of the most complex neurological conditions written in plain language packed with expert insight and created with compassion As the sole author it's been my mission to offer a clear supportive and practical resource for those living with MSA and their families You'll gain the confidence to face the condition understand its challenges and take meaningful action This book bridges the gap between diagnosis and daily life bringing clarity where there's confusion and comfort where there's worry It's not just about information it's about helping you live well through lifestyle insights symptom management and supportive care planning Whether you're newly diagnosed or caregiving for someone with MSA this guide offers the tools you need to feel informed hopeful and empowered Inside you'll discover how to Clearly understand what MSA is how it develops and how it's different from Parkinson's Recognize early warning signs including tremors speech issues blood pressure drops and more Navigate the diagnostic process with confidence imaging testing and medical teams Explore known causes risk factors and current research on genetics and brain cell changes Develop practical routines and create a safe home environment for daily living Address nutrition sleep fatigue and emotional well being Understand available treatments medications therapies and experimental options Find caregiver support prevent burnout and plan long term care needs Prepare for end of life care with compassion respect and clarity Connect with support groups read real patient stories and find hope amid the diagnosis Get direct answers to common concerns and questions about MSA This guide is more than a book it's a lifeline for patients and caregivers Don't let uncertainty define your journey Take control find clarity and step into each day with strength Add this book to your cart now and begin your journey to greater understanding and support

Multiple System Atrophy: Pathophysiology, Diagnosis, and Comprehensive Management Strategies Dr. Spineanu Eugenia, 2025-02-19 This comprehensive treatise on Multiple System Atrophy MSA delves into the complexities of this rare neurodegenerative disorder exploring its pathophysiology clinical features and diagnostic criteria The work examines the latest advances in biomarker discovery highlighting the significance of early detection and differential diagnosis from similar conditions It discusses pharmacological and non pharmacological interventions including the role of lifestyle modifications such as diet exercise and stress management in enhancing patient quality of life Additionally the treatise addresses current clinical trials and novel therapeutic targets paving the way for future research in MSA treatment options By integrating medical insights with practical strategies this treatise serves as an essential resource for healthcare professionals researchers and patients alike

aiming to improve understanding and management of Multiple System Atrophy Explore this in depth analysis to gain valuable knowledge on MSA and contribute to ongoing discussions in the field of neurodegenerative disorders **Living Day by Day**

With MSA Bill Sydnor, 2020-08-12 A 10 year journal of living with degenerative neurological disease *Quantitative Image Analysis of the Rostral Pons in Patients with Multiple System Atrophy* Jeffrey T. Walburn, Charles Frank Ide, 2010 Multiple System Atrophy MSA is a sporadic neurodegenerative disease with varied clinical phenotypes that include Parkinsonism and cerebellar and autonomic dysfunction Glial cytoplasmic inclusions GCIs aggregates of the presynaptic protein insert alpha synuclein appear in oligodendrocytes in MSA In this study the amount of alpha synuclein was measured in multiple regions of the rostral pons using quantitative image analysis Alpha synuclein was significantly increased in the dorsal most tract in adjacent non pontocerebellar fiber tracts corticopontine corticobulbar corticospinal and in the central tegmental tract of MSA patients compared to controls The distribution of alpha synuclein in these specific tracts is consistent with pontocerebellar involvement in MSA In addition the amount of alpha synuclein in the four analyzed regions varied amongst MSA patients and may be associated with the severity of specific symptoms in different patients Increased amounts of alpha synuclein in the dorsal most pontocerebellar fiber tract correlated with changes in global gene expression most notably changes in genes associated with oligodendrocyte and mitochondrial functions the inflammatory stress response and protein degradation processes **One Step at a Time** Angela MacLauchlan, 2016-06-21 This book is about ataxia and multiple system atrophy two rare conditions that I have to live with It was originally written for my adult kids to begin with explaining it to them so they hopefully would understand what ataxia and MSA is and can do to someone Then to help spread ataxia awareness so many people have never even heard of these conditions let alone know anything about them **The Definition of Multiple System Atrophy** Peter L. Lantos, 1998

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