

HIGHLIGHTS FROM THE
**NIH State-of-the-Science Symposium on
Myelodysplastic Syndromes (MDS)**

*A Summary for Patients with Myelodysplastic
Syndromes (MDS) and their Caregivers*

 **Aplastic Anemia & MDS**
INTERNATIONAL FOUNDATION

The Aplastic Anemia & MDS International Foundation (AA&MDSIF) is committed to providing patients and their families with answers, support, and hope. Keeping patients up to date on the latest scientific breakthroughs and promising research is a significant part of the AA&MDSIF mission. We do this by:

- ◆ Reporting research findings with the most direct relevance to patients through AA&MDSIF email News Alerts, our Web site, our monthly eInsider, and our print publications
- ◆ Sponsoring patient conferences and webinars where experts present the most current information on MDS and how the latest knowledge affects disease diagnosis, treatment, and management
- ◆ Interpreting progress in the causes and treatment of bone marrow failure diseases presented at key professional conferences

This booklet provides a summary of the State-of-the-Science Symposium on Myelodysplastic Syndromes (MDS) convened by the National Heart, Lung and Blood Institute (NHLBI) of the National Institutes of Health (NIH) in Bethesda, Maryland on September 7-8, 2011. Although the information in this booklet has undergone a thorough, independent medical review to ensure its accuracy, this information is not intended to be a substitute for the advice of your doctor. You should always seek medical advice from a qualified physician.

The booklet was written by Debby Berlyne, PhD, in consultation with David Steensma, MD.

For more information, call us at (800) 747-2820, or visit us online at www.AAMDS.org.



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Dear Patient or Caregiver,

On September 7th and 8th, 2011, the National Heart, Lung, and Blood Institute (NHLBI) of the National Institutes of Health (NIH) hosted a State-of-the-Science Symposium on MDS in Bethesda, Maryland. The purpose of the symposium was to hear from experts in the field about recent discoveries and to identify knowledge gaps and opportunities related to MDS diagnosis, treatment, and research. NIH plans to use the information from the symposium to focus its research and funding agenda on the most promising areas to address the unmet needs of people living with MDS.

The symposium brought together 170 scientists and clinicians from academic centers, federal agencies, pharmaceutical companies, and nonprofit organizations in the United States, Europe, and Australia. Presenters discussed progress in research on MDS biology, with a focus on genes and related molecular findings. They also summarized recent studies on tools to classify different MDS subtypes, predict the course of the disease, and identify which treatments will work best in different types of patients. Meeting participants discussed the benefits and limitations of existing MDS treatments. Finally, they identified many research questions that still need to be answered.

This summary of the NIH State-of-the-Science Symposium on MDS is intended to help patients and their caregivers learn about all of the progress that has been made in understanding the disease and how that knowledge affects its treatment. We do not intend to recommend or endorse any particular medication or treatment approach. Our goal is simply to inform you about the current state of MDS research and how it may affect the diagnosis, therapy, and prognosis of patients in the near term as well as the more distant future.

In addition to this booklet, AA&MDSIF presented a webinar on September 29, 2011 entitled *News from the National Institutes of Health State-of-the-Science Symposium on MDS: What We Now Know and What It Might Mean for Patients*. This booklet includes information discussed during the webinar in addition to the symposium to further clarify what is known about MDS and what key research questions need to be addressed.

By learning more about the scientific aspects of MDS, both patients and caregivers can make more informed decisions about treatment options and management of the disease.

As always, please contact AA&MDSIF if you have questions about this summary or any aspect of managing your disease.

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Member, AA&MDSIF Medical Advisory Board

News from the National Institutes of Health State-of-the-Science Symposium on MDS: What We Now Know, and What It Might Mean for Patients

Now Available on the Online Learning
Center (OLC): www.AAMDS.org/Learn

On September 29, 2011, AA&MDSIF produced a webinar featuring David Steensma, MD of the Dana-Farber Cancer Institute discussing the most relevant information for patients from the NIH State-of-the-Science Symposium on MDS. This webinar program is now posted on the Online Learning Center and is available for viewing in addition to the audio presentation and accompanying slides.

To view this and other archived webinars, visit our Online Learning Center and choose Archived Webinars.

The Online Learning Center (OLC) is your comprehensive information source on all aspects of bone marrow failure diseases. Created expressly for patients and their families, caregivers and advocates, all OLC content is free and available to anyone with access to a computer and a high-speed Internet connection. In addition to archived webinars, here is what else you can find on the OLC:

- Live webinars conducted by the nation's leading experts
- Innovative interactive learning modules
- Interviews with experts on aplastic anemia, MDS and PNH

More than 30 programs are now available, and more are being added all the time. Here are just a few:

- Advances in Treatment: What's on the Horizon for MDS Diagnosis and Treatment?
- Bone Marrow Transplantation for MDS
- Complementary and Alternative Therapies: Myths, Realities and Opportunities
- Fundamentals of Hematology and Bone Marrow Failure Diseases
- Iron Overload: Prevention, Diagnosis and Treatment
- Managing Fatigue in Bone Marrow Failure Diseases
- MDS: Current Thinking on the Disease, Diagnosis and Treatment
- To Treat or Not to Treat: Making Treatment Decisions in MDS
- Treating Higher-Risk MDS
- Understanding FDA-Approved Drug Therapies for MDS: What to Expect from Treatment

AA&MDSIF Online Learning Center: www.AAMDS.org/Learn



Read what one patient had to say about the AA&MDSIF Online Learning Center:

The live and archived webinars and the interviews are an invaluable source of information about bone marrow failure diseases such as mine. Whenever I have questions, the Aplastic Anemia & MDS International Foundation is always my "go to" source for answers. Thank you so very, very much for the knowledge and support you provide.

- Charles (MDS patient)



Don't have Internet access? Go to your public library or local community center, or ask a friend or family member to help you the next time you visit.

NIH State-of-the-Science Symposium on Myelodysplastic Syndromes (MDS)

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PATIENT CHARACTERISTICS

In 2001, the National Cancer Institute began tracking MDS in its Surveillance, Epidemiology, and End Results (SEER) cancer registry. An analysis of SEER data, along with a review of Medicare claims data, showed that MDS is more common than previously thought. This type of information could help bring more funding to research on MDS.

Based on research from a German patient registry, about 4 out of 100,000 people develop MDS each year. However, estimates based on insurance claims data suggested that MDS may be several times more common. The disease is more common in men than women, and its frequency increases sharply with advancing age. A comparison of MDS patients from Germany and Japan found that patients in the two countries tend to have different genetic mutations (changes in genes). This type of information could eventually help doctors understand the course of MDS based on the racial and ethnic background of each patient.

Most people with MDS have at least one other disease or condition unrelated to their MDS, known as a co-morbidity. Many patients, for example, have heart disease, high blood pressure, or diabetes. Along with advanced age, having comorbid conditions contributes to poorer outcomes for people with MDS. Researchers are learning more about patient comorbidities and their effects on MDS.

Stem cell transplantation is the only way to cure MDS. Because most patients with MDS are older than 65 and tend to have other diseases and conditions besides MDS, they are often not eligible for a transplant. The use of stem cell transplantation is growing, however. Some older patients in their 60s or early 70s are now eligible for the procedure and new sources of stem cells (such as from unrelated donors or umbilical cords) are now available.

About 10–20% of patients with MDS develop acute myelogenous leukemia (AML). Most patients with MDS die from complications of MDS such as infection, however, not AML.

Understanding of the biology of MDS has exploded in recent years. This knowledge is critical for developing new MDS treatments.

Causes of MDS

In 85% of cases of MDS, the cause of the disease is unknown. In the other 15% of cases, MDS is due to inherited factors or exposures to something in the environment. In very rare cases, MDS runs in families.

Researchers have now identified many genes associated with syndromes and diseases—such as Down syndrome and Fanconi anemia—that increase the likelihood of developing MDS. Studies have also shown that certain treatments, including some radiation and chemotherapy treatments for cancer, can cause MDS. Finally, people sometimes develop MDS after exposure to chemicals and other environmental hazards, such as:

- ◆ Benzene
- ◆ Tobacco smoke
- ◆ Hydrocarbon solvents
- ◆ Ionizing radiation
- ◆ Pesticides, weed killers, and fertilizers

How much people need to be exposed to each of these hazards to develop MDS is unknown and likely varies from person to person.

The immune system, which helps the body protect itself from infections, might play a role in some cases of MDS. In autoimmune disorders, the body's immune system attacks the body. People with certain autoimmune disorders—such as Crohn's disease and certain types of arthritis—have a higher risk of MDS than people without these disorders. Experts believe that several types of cells that play a role in the immune system do not work properly in patients with MDS. This information might help doctors figure out which patients with MDS might benefit from immune therapy.

Bone marrow stem cells are the seed cells that make blood cells. These stem cells play an important role in developing MDS. Treatments therefore need to target these stem cells. New research shows that changes in the microenvironment, or the environment in which the bone marrow stem cells live, affects their ability to make healthy blood cells.

MDS Development

Experts used to think that when patients were first diagnosed with MDS, most of their blood cells were healthy and only a few were abnormal. But studies using new technologies have shown that by the time patients are diagnosed with MDS, many of their blood cells are already abnormal. Once the MDS progresses to AML, even more blood cells become abnormal. Understanding the evolution of these cells will help researchers target treatment to changing cells. This information will also help experts monitor treatment, especially after stem cell transplantation.

Role of Genes

As a result of new technologies, researchers have recently identified many mutations in genes in blood and bone marrow cells that seem to play a role in MDS. Just five years ago, research had identified only three genetic mutations. Now, more than 25 genetic mutations are known to play a role in MDS, showing how quickly the field is growing.

This new genetic information helps scientists understand the biology of MDS. This information could also be useful for diagnosis and to predict a patient's course of disease. In the near future, doctors might be able to use information on genetic mutations in patients with MDS in combination with the International Prognostic Scoring System (IPSS, described in the section on classification systems below), to choose the best treatment for them.

Patients with MDS who have mutations in some of these genes may not survive as long as patients without the mutations. Patients with some of these mutations tend to survive for more time or less time than the IPSS would predict. Studies have also identified several genetic mutations that are more common in people who develop MDS after certain cancer treatments. Abnormal DNA methylation, a chemical process that helps control gene activity, is one of the hallmarks of MDS that progresses to AML.

Researchers need to identify the effects of genetic mutations on disease features using the latest technologies. This research will require blood and bone marrow specimens from large groups of patients with MDS, along with specimens of normal tissue and detailed information from each patient and his or her family. This genetic information could be useful for classifying MDS into different subtypes to predict the course of each patient's disease and choose the best treatment for each patient.

Classification Systems

Scoring and classification systems are useful for predicting the progress of MDS in different patients and how likely these patients are to survive. Doctors also use this information to choose the right treatment for each patient.

The International Prognostic Scoring System (IPSS) is a tool that doctors use to classify a patient's MDS into four risk categories. These include low-risk, intermediate-1, intermediate-2, and high-risk. A risk score is developed for a patient's disease based on three factors:

1. The percentage of blasts, or immature white cells, in the bone marrow
2. The number and severity of chromosome changes in bone marrow cells
3. The number of low blood counts, also called cytopenias

The IPSS uses information that doctors can easily collect, but the system has some weaknesses. The IPSS does not account for many factors that can affect the patient's outcomes, such as age, fibrosis (scarring of bone), ferritin (iron marker) levels, genetic mutations, co-morbid conditions, or severity of low blood counts. So patients with the same IPSS score can, in reality, have very different risks of progression to AML and survival. Also, the IPSS was originally developed and tested with patients who had not yet been treated for their MDS, so it is not designed to provide an accurate prognosis after treatment has begun. The IPSS can only be used at the time of diagnosis, not on an ongoing basis.

Experts recently recommended changing the IPSS based on information from 12 countries to classify patients into five groups: very good, good, intermediate, poor, and very poor. The Revised IPSS (IPSS-R) score, which ranges from 0 for the lowest risk to 18 for the highest risk, is based on the same factors as the IPSS, but emphasizes cytogenetic abnormalities (genetic changes) more than high blast counts. The IPSS-R includes more information than the IPSS. The system has now been published and is available for doctors or patients to use.

Like the IPSS, the IPSS-R is designed only for patients whose MDS is not caused by prior chemotherapy or radiation treatment. It still does not take into account the severity of low blood counts or the new understanding of genetic mutations. The IPSS-R can only be used at the time of diagnosis (before patients receive treatment that could change the course of their disease).

In the IPSS-R, like the IPSS, each risk group is associated with a different average length of survival and likelihood of developing AML. Not surprisingly, patients in the very good group tend to survive longest (nine years, on average) and are least likely to develop AML. These averages might not apply to patients who have had treatment that could improve their survival. Doctors are not yet using the IPSS-R for their patients with MDS because its accuracy is still under review.

The World Health Organization (WHO) revised its classification system for MDS in 2008. The WHO Classification System places patients into seven different MDS subtypes. These subtypes are based on the number of low blood counts, proportion (less than 5% or 5–10%) of immature cells in the bone marrow (blast cells), whether the new red blood cells in the bone marrow have rings of iron deposits around the nucleus, which types of marrow cells look abnormal, and whether the bone marrow chromosomes are missing part of chromosome 5.

DIAGNOSING AND CLASSIFYING MDS

MDS Diagnosis

The MDS classification and prognostic tools depend on the pathologist's ability to count blast cells in a patient's bone marrow sample. This is difficult because abnormal blasts do not look very different from normal blasts. Some studies have shown that in about 15% of cases, pathologists do not diagnose MDS accurately or do not classify MDS correctly. Experts at the symposium recommended that pathologists with expertise in MDS be consulted to evaluate bone marrow samples from patients with suspected MDS.

Biomarkers

In the future, researchers hope to find biological markers, known as biomarkers, that may be used in patients who have and have not had treatment for their MDS. The biomarkers would ideally be measurable in doctors' offices and hospitals, and screening patients for these biomarkers must be affordable.

In addition to helping doctors predict the course of MDS and select the right treatment for each patient, biomarker research could help scientists better understand MDS. In particular, this research could provide information on how normal bone marrow cells become MDS cells, how MDS progresses to AML, and why blood counts worsen in patients with MDS.

Researchers are studying several biomarkers that can help them better understand, diagnose, and classify MDS. These include:

- ◆ Age
- ◆ Blood cell counts
- ◆ Other diseases and conditions in patients with MDS
- ◆ Transfusion dependency
- ◆ Fibrosis, or scarring, in the bone marrow
- ◆ Mutations in genes
- ◆ Chromosome abnormalities
- ◆ Blood iron levels
- ◆ Telomere length

The tools scientists are using to measure potential biomarkers include:

- ◆ Flow cytometry, a laboratory technique that measures the properties of cells
- ◆ Gene expression profiles to measure the activity of different genes
- ◆ Immunohistochemistry, a method to identify antigens, or other substances in the body that might help researchers identify events involving genes

Treatments

In general, MDS treatment can improve quality of life, especially if the treatment reduces the need for regular blood transfusions. Specific benefits of treatment may include less fatigue, less psychological distress, and better physical functioning. The best way to improve quality of life in patients with MDS is to help their bone marrow make healthy blood cells.

Patients with certain genetic mutations seem to be more likely to respond to treatment with hypomethylating agents or lenalidomide, but more research is needed to confirm this. According to some recent data, patients with certain characteristics, such as being older, male, or having a higher bone marrow blast count, are less likely to respond to azacitidine treatment than other patients. Studies have also found that certain characteristics, such as a high IPSS score, are associated with death or relapse after allogeneic stem cell transplantation in patients with MDS.

A promising approach to predicting response to treatment is genome-wide association studies. A person's genome has all of his or her DNA, including all of that person's genes. In these studies, researchers scan genomes of many patients to find differences in genes that are more common in people with the disease. The cost of this technique is dropping quickly. By shedding light on MDS biology, genome-wide association studies will help researchers find better treatments.

In the last 10 years, the U.S. Food and Drug Administration has approved three new drugs for MDS treatment: azacitidine in 2004, lenalidomide in 2005, and decitabine in 2006.

Presenters at the symposium gave updates on the latest MDS treatment research. The treatments they discussed included:

- ◆ *Allogeneic stem cell transplantation:* Allogeneic stem cell transplantation is the only treatment that can cure MDS. A stem cell transplant replaces the immature and unhealthy cells that form blood cells in the bone marrow. The transplants are allogeneic when the cells come from a donor who is not the patient. This is not a good treatment option for patients with lower-risk MDS because it could worsen their survival, but it may be appropriate for patients with higher-risk MDS.
- ◆ *Chemotherapy:* Available chemotherapies that are similar to those used for acute leukemia do not improve survival in patients with MDS. Researchers are studying some new chemotherapies that might be effective in people with MDS, such as clofarabine, sapacitabine, and rigosertib.
- ◆ *Erythropoietin-stimulating agents (ESAs):* ESAs encourage the body to make more red blood cells. The U.S. Food and Drug Administration has not approved ESAs for MDS because of the lack of randomized clinical studies and concerns about ESA safety of in patients with solid tumors, such as breast cancer or lung cancer. But research has not shown that these drugs increase the risk of AML in MDS, and they may improve survival. Researchers are now studying the reasons why some patients respond to ESAs for a while, but then have a relapse.
- ◆ *Hypomethylating agents:* Hypomethylating, or demethylating, agents help the bone marrow of patients with MDS function normally and kill unhealthy cells. Vidaza® (azacitidine) and Dacogen® (decitabine) are examples of hypomethylating agents. These treatments can improve survival, and recent trials have shown that they can be effective in patients with high- and low-risk MDS.

DIAGNOSING AND CLASSIFYING MDS

These drugs don't cure MDS, and the average response lasts about 14 months. About half of patients with MDS do not have improved blood counts after treatment with these drugs.

To make these drugs more effective for MDS, researchers are now testing different dosing schedules of hypomethylating agents. They are also studying combinations of these drugs with other drugs. Some studies have had promising results for a combination of vorinostat, a histone deacetylase (HDAC) enzyme inhibitor, or lenalidomide (see below) with a hypomethylating agent.

- ◆ *Iron chelation:* Patients with MDS who have had many red blood cell transfusions may develop high levels of iron, known as iron overload. Iron overload can damage the body's tissues and organs. Patients with MDS who need blood transfusions do not survive as long if they have iron overload as patients without overload.

Iron chelation drugs can remove the extra iron from the body. Some research shows that iron chelation might be able to reduce the risk that MDS will progress to AML, improve cytopenias (shortages of red blood cells), and increase survival. Studies of iron chelation drugs are ongoing.

- ◆ *Lenalidomide:* Revlimid® (lenalidomide) is useful in some patients with lower-risk MDS or 5q-syndrome. This drug reduces anemia in patients with MDS. Patients who respond to this treatment are less likely to develop AML, and they survive longer than patients who do not respond to the treatment. About one quarter of patients without 5q-syndrome who have low-risk MDS stop needing blood transfusions after lenalidomide treatment.

Patients with certain genetic mutations are less likely to benefit from lenalidomide. Also, patients who do not have thrombocytopenia (shortage of platelets in the bloodstream) when they start lenalidomide treatment are more likely to respond to the treatment if they develop thrombocytopenia or neutropenia (shortage of white blood cells) after starting the treatment than those who do not develop these cytopenias.

- ◆ *Alemtuzumab:* Campath® (alemtuzumab) is a monoclonal antibody, or artificial protein, that the immune system uses to fight foreign bodies. In one Phase II clinical trial, patients with intermediate-1 and intermediate-2 MDS with features likely to predict a good response to immunotherapy had a high rate of response to alemtuzumab treatment. After a year, some of these patients had normal blood counts and no longer needed blood transfusions. Other types of immunotherapy include ATG, cyclosporine, and tacrolimus.

Some of the questions about existing MDS treatments that research needs to answer are:

- ◆ Are azacitidine and decitabine equally good, or is one better than the other?
- ◆ When should doctors stop an MDS therapy if it isn't working?
- ◆ What are the best schedules and doses for each treatment?
- ◆ Is lenalidomide effective in patients without 5q-syndrome?
- ◆ How safe are growth factors (such as ESAs)?
- ◆ How can doctors combine some of the MDS treatments to make them more effective?

BONE MARROW FAILURE SYNDROMES

When someone has a bone marrow failure syndrome, their bone marrow cannot make blood cells. Patients inherit some of these syndromes from their parents. Others are a result of exposure to radiation, drugs, chemicals, or viruses, possibly in combination with certain genetic mutations.

Some people with certain bone marrow failure syndromes develop MDS or AML during childhood. The World Health Organization has developed a classification system for MDS of childhood with four categories: familial (inherited), therapy related, primary, and secondary (due, for example, to an inherited bone marrow failure syndrome). “Primary” MDS of childhood is probably familial, although not everyone in the family who carries the genetic mutation has the disease.

Some of these syndromes are described below:

- ◆ *Fanconi anemia (FA)*: FA is an inherited bone marrow failure syndrome that can affect every system in the body. Children with this disorder are often born with birth defects, many develop leukemia at a young age, and about half develop MDS by age 50. The disease symptoms get worse over time.
- ◆ *Dyskeratosis congenita (DC)*: The symptoms of DC include abnormal fingernails and toenails, uneven skin coloring, and white patches in the mouth. About 30% of these patients develop MDS and 10% develop AML by age 50. People with DC have very short telomeres, or regions at the end of chromosomes. Telomere measurements are therefore an ideal screening tool for DC.
- ◆ *Severe congenital neutropenia (SCN)*: People with SCN have low white blood cell counts, so they tend to develop serious infections starting in infancy. About 22% of these patients develop MDS or AML by age 50.
- ◆ *Diamond-Blackfan anemia (DBA)*: DBA is associated with an inability of the bone marrow to make enough red blood cells, leading to anemia. Symptoms do not usually start until after childhood. These patients have a small risk of developing MDS, AML, or bone cancer.
- ◆ *Shwachman Diamond syndrome (SDS)*: Patients with this inherited disorder tend to have low white blood cell counts and defective bone formation. They might also have problems digesting food because their pancreas does not make enough enzymes to help break down food. About 30% of people with SDS develop MDS or AML by age 40.

If a patient develops MDS before age 40–50, their doctor should test that patient for an inherited bone marrow failure syndrome. Patients with one of these syndromes should have a stem cell transplant soon after diagnosis.

These patients often need different preparatory treatments before stem cell transplant than patients without these syndromes. Also, if a patient has an inherited bone marrow failure syndrome, they should not get a stem cell transplant from a family member who carries a genetic mutation for that disorder.

FUTURE RESEARCH

Researchers need a large set of high-quality MDS specimens with detailed information on each patient (such as what treatments each patient has had and the history of their MDS). Accelerating research in MDS will require centralizing existing collections of normal and MDS tissue samples from patients with MDS.

Other research needs include:

- ◆ Figuring out which of many recently identified genetic mutations play an important role in MDS
- ◆ Understanding the connections between genes, MDS features, and responses to treatment
- ◆ Finding a practical and affordable way to screen patients for important genetic mutations to better match treatments to patients
- ◆ Adding information on genetic mutations to the IPSS to increase its accuracy
- ◆ Improving stem cell transplantation for MDS by using new insights into MDS biology and new technologies
- ◆ Determining the effect of epigenetic changes, or genetic changes that are not due to changes in DNA structure, in MDS biology
- ◆ Using knowledge of epigenetic changes to develop better MDS treatments

WHAT YOU CAN DO

If you have MDS, take care of yourself, and don't let the disease define you. You are still the person you have always been, and you still have a lot to offer. If you have always enjoyed gardening or singing, for example, keep doing those things. The fatigue associated with MDS treatments can make it hard to carry on your normal activities, but don't let the disease take over your life.

Be sure to communicate often and work in close partnership with your physician. You need information about MDS and its treatments so that you can advocate for yourself. If you think you qualify for a clinical trial, consider participating. Your doctor or MDS specialist can give you more information about ongoing clinical trials. To learn more about clinical trials, visit www.AAMDS.org/about/MDS/clinical-trials or www.ClinicalTrials.gov.

Support MDS patient advocacy organizations, such as AA&MDSIF, which provide information that can help you understand the disease. These organizations are working to increase the amount of research on MDS. With support from people like you and your loved ones, they can make a difference.

MORE WAYS TO GET HELP

The Aplastic Anemia & MDS International Foundation (AA&MDSIF) is here to help. We provide the following services:

- ◆ Personalized support from patient educators
- ◆ Free educational materials on many topics related to MDS
- ◆ Online Learning Center
- ◆ Patient and family conferences
- ◆ Peer Support Network
- ◆ Print and electronic newsletters with important information and updates
- ◆ Clinical trials information

Contact us today. Here's how:



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Go to our Web site:

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Remember – you are not alone. We are standing by to support you in any way we can.



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