



**A patient's and caregiver's guide for
an autologous transplant**

HOW TO USE THE INFORMATION IN THIS GUIDE

This guide is a resource to help you and your family learn about blood and marrow stem cell transplantation at City of Hope. Understanding what a transplant is, why it has been recommended for you, and what to expect during treatment may help answer your questions and relieve some of your worries.

Our goal is to provide you with the best possible medical care, nursing care, support and communication as you move forward through your treatment plan.

Tips for using this guide

- This guide can be used as a reference to prepare for transplant. You can either read it beginning to end, or read the sections that are most important to you at first, then go back and read other sections as they become important.
- Bring this guide with you to your clinic appointments. Your nurses will use it to help teach you about different aspects of your care.
- Write your notes in it. Add important information to it. Personalize it. Make it your own.

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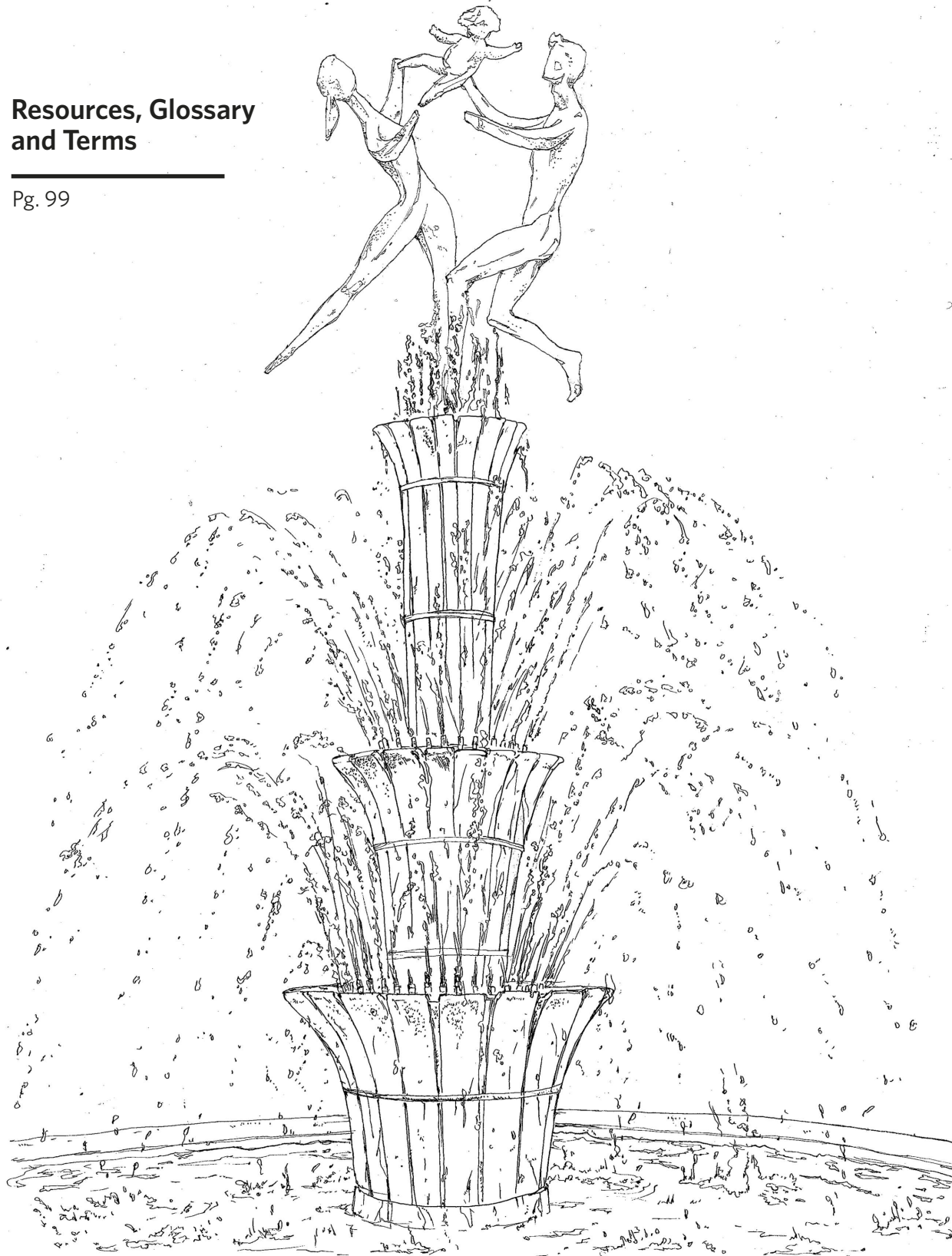
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A Letter from a Bone Marrow Transplant Survivor and Thriver

Welcome to your patient guide to blood and marrow stem cell transplantation! You are about to embark on one of the most amazing experiences of your life! How do I know? In the summer of 2012, I took my journey, which transformed my life in so many ways! For so many us, venturing into the unknown is a daunting task. The key is preparation. For me, I started with prayer and meditation, relentless positivity, followed by a lot of laughter, self-education, talking to other bone marrow transplant survivors, and building good relationships with my doctor and medical team. Don't underestimate the power of positivity and laughter, when venturing into the unknown. Remember, you can choose how you would view your journey ahead of time, it all comes down to perspective! I will share more insight on this later.

I am happy to shout out at the top of my lungs, that I am now a survivor and thriver! I started to see myself as a thriver somewhere along the way, when I had an epiphany that my journey was not just about surviving, it was about having this renaissance period in my life, and how lucky I was to have this opportunity. During this journey, I had many family members and friends supporting me every step of the way. I will also forever be grateful for the dedicated City of Hope medical teams that saved my life. In the many months following my recovery of the transplant, I experienced what I have come to appreciate was a retreat with myself. I learned that the purpose and vision for my life had deepened and had become multifaceted. For humanitarian purposes, I happily embraced my need to reach out and help other bone marrow transplant patients, as well as other cancer patients. I can still see myself in all of you! I will always carry a very special part of the transplant community with me.

Each of you have the opportunity to lift a "blue print" for yourself from the pages of this guide, to help you connect and persevere through the various stages of bone marrow transplantation. I can say from experience, that arming yourself with knowledge is one of the most invaluable steps you can take to maintain your piece of mind. This guide can be seen as a mini life manual to help you prepare for the bone marrow transplant, and help you step by step during and after the transplant process. The guide is comprehensive, as it is thoughtful; tackling a myriad of topics and issues where you as the patient can take comfort that City of Hope's medical staff is truly looking out for your well-being.

I have learned that self-discovery and resourcefulness can serve as a powerful aid to help you on your journey, throughout your journey, and long after the journey is over. Haven't you ever wondered what you might be made of at any given time, perhaps at a defining moment in your life? What about the 10K or the marathon you have promised yourself you would conquer all these years, or the personal best you vowed to set in the very next Race for the Cure? Well, this could also be your chance of a life time to be empowered in your very own way. I realized, sometime later, that this added benefit helped me to achieve the seemingly elusive peace of mind.

I have always been naturally curious about life, and the unexpected circumstance it can bring to a seemingly ordinary life, on often an ordinary day. I remember reading comedian Gilda Radner's book, "It Is Always Something," two years prior to my diagnosis. Learning about her self-awareness, tremendous courage and tenacity, helped to ignite the energy and perseverance that I would later need when my own journey had arrived. My mother raised my brothers and me to be our own best friend and to enjoy our own company at all times (even in times of peril). My own self discovery, revealed that I am a good balance between positivity and realism. The balance of these traits along with my mother's gifts, served me well during my experience. After taking a tour of City of Hope a year in advance of my transplant, to familiarize myself with the grounds, I started to envision myself living here in the next year. I started making plans then. How did I want to live my life during the prescribed 30-day stay here at City of Hope? My main goal was to ensure that I would create the best possible home away from home once I was assigned to a hospital room. I assured myself I would be a great patient, and at the same time, remain vigilant about my own needs. I knew I would always wear my greatest accessory, my smile. In my arsenal of life strategies, there is a certain quote that I tend to draw strength from as well. Remember the movie "Mary Poppins?" "A spoon full of sugar makes the medicine go down," it really does! Think about it, a quote like this can help you make the choice to have a positive experience and perhaps an "educational view" of an event that is life changing; and challenges you to reexamine your view point.

When move-in day came, I practically transformed my room into a suite, making it colorful and cozy seemingly with a few brush strokes. Heartfelt cards from well wishers and conversation pieces were interwoven between heartwarming pictures of family and friends carefully placed at eye level in my suite where I could see them daily. Life-like silk flowers and plants, seemingly always in bloom, served as my faux garden, to replace real plants, which are not allowed in patient rooms. I always made sure I had music softly playing in the background, to ensure just the right ambience. Before I knew it, I was clicking my heels. My suite had indeed become "home, sweet, home." I had no idea that medical staff and my visitors would enjoy coming to my room so much.

My panoramic size window facing the San Gabriel Mountains was a breathtaking visual for me to take in each and every day. I wore colorful clothes, and in some ways, treated my stay like a spa treatment — especially taking full advantage of every therapy offered. My husband's particular brand of humor was always hysterical and kept me on my toes. Having your loved ones walk with you on your journey is well beyond words, and I can truly say he was heaven sent. My one and only son was and continues to be my biggest fan. There were times I knew he just wanted to do whatever he could do to help me feel better, and ironically, I found myself helping him to feel better

in his time of need. He continues to celebrate me today. My youngest brother was my donor, and I will forever be grateful for his courageous and selfless act. My oldest brother was the “locomotive” for anyone involved with my care. I journaled by using an online computer application which allowed me to keep family and friends informed on my progress.

Keeping my mind sharp was (and still is) very important to me. You never know, you might find that writing puts you in touch with your inner Hemingway, Grisham or Steinbeck. I remember reflecting on the timeless writings of Langston Hughes, Anais Nin and James Baldwin, who are among some of my favorite authors. Perhaps, you are more of a poet, maybe taking cues from poets that have come before you, from Oscar Wilde to James Joyce and Gertrude Stein to Maya Angelou. Taking part in the music therapy class might reveal that song that is in all of us! The possibilities only you know. Can you see yourself belting out trumpet compositions by the great Lewis Armstrong or Wynton Marsalis? Maybe the undisputed sound of Santana, or the extraordinary versatility of cellist Yo Yo Ma is more your speed. Can you imagine yourself performing on Broadway? Yes, on Broadway! You get the point, let your imagination help you and work for you, you have the time, right? I am still trying to hit the glass shattering high octave notes of Audra McDonald, Mariah Carey and Celine Dion. What note lies inside of you? How about the art therapy class. With my creativity just bursting at the seams, I could hardly wait for my project to take shape. I am still so proud of the life-like wooden snake I painted in jewel tones, and gave to my son as a keepsake of my journey. My point is, try to be open to all of the self discoveries that your own journey can bring you. Realize they are all gifts!

As you learn how to use this guide, it will become increasingly clear how important self-care is as it relates to your emotional, social, and physical needs following your bone marrow transplant. City of Hope’s medical team and your own support system will prove vital to your own well-being. As you celebrate this major landmark in your life, you can now move forward with a “new blueprint” to help you to accomplish your dreams and goals to lead a fruitful life.

If I could make one last suggestion to you, following your journey here at City of Hope, consider “paying it forward”, there is always another patient who is in need of our help. I found this guide to be a great tool and companion, it will help to bolster your knowledge, insight and comfort as you journey through this amazing experience. It has been my honor and pleasure to share this very precious moment in my life with each and every one of you. Remember, you have the power to define your moment!

Sincerely,

Patrice A. Traylor

Bone marrow transplant
survivor and thriver

2012





"A must read for every
bone marrow transplant patient."

— BMT Survivor

Welcome to City of Hope

INTRODUCTION

- National Cancer Institute Designation
- City of Hope's Philosophy of Healing
- History of Blood and Marrow Stem Cell Transplantation at City of Hope

01

Introduction

Welcome to City of Hope

A NATIONAL LEADER IN CANCER CARE

Founded in 1913, City of Hope is a national leader in cancer care. We provide each patient with an individualized, comprehensive care experience and deliver the highest quality treatment and expertise.

We are one of only 52 National Cancer Institute (NCI)-designated comprehensive cancer centers in the U.S. The NCI designation recognizes excellence in treatment, research and expertise to address the many faces of the disease, whether in early or late stage, and for common or rare types of cancer.



“THERE IS NO PROFIT
IN CURING THE BODY IF,
IN THE PROCESS,
WE DESTROY THE SOUL.”

City of Hope is also proud to be a founding member of the National Comprehensive Cancer Network (NCCN), reflecting our national leadership in advancing research and treatment. NCCN member institutions are recognized for their world-renowned experts and for treating complex, rare and aggressive forms of cancer.

Most importantly, we firmly believe in providing value across the entire patient journey. At City of Hope, this is measured by the experiences and outcomes that our treatments and dedicated team provide. Our goal is to care for the whole person, so that life during treatment and after cancer can be rich and rewarding.

CITY OF HOPE'S PHILOSOPHY OF HEALING

In 1951, former City of Hope Executive Director Samuel H. Golter wrote City of Hope's "Thirteen Articles of Faith," which stress one common philosophy:

"There is no profit in curing the body if, in the process, we destroy the soul."

Today, City of Hope's family of highly skilled researchers, doctors, nurses and caregivers still share this philosophy. They stand at the heart of a medical center which focuses on cancer research, and blood and marrow transplantation. City of Hope clinicians are committed to using the discoveries made in the laboratory to create new and effective cancer treatments for our patients. Supported by an international network of donors and volunteers, their work is grounded in deep compassion and respect for each person who turns to City of Hope for help.

City of Hope brings together a health care team of professionals with a common goal to provide the best and most appropriate cancer treatment possible. Because City of Hope takes a comprehensive, multidisciplinary approach to cancer therapy and patient care, City of Hope team members not only create treatment plans that promote the extension of life, but also customize supportive care plans that improve the quality of life.

HISTORY OF BLOOD AND MARROW STEM CELL TRANSPLANTATION AT CITY OF HOPE

In 1976, City of Hope became one of the first six medical centers in the country to begin treating leukemia patients with blood and marrow transplantation. Today, City of Hope is a pioneer in bone marrow and stem cell transplants. As one of the largest and most successful programs of its kind in the U.S., our program attracts patients across the nation and world.



“Once I began to understand the individual roles of the medical staff, I realized it was such a comfort to me.”

— BMT Survivor

Your Health Care Team

02

Your Health Care Team

At City of Hope, we use a multidisciplinary approach with a team of many different kinds of health care providers coming together to care for you. You and your family are the most important part of your health care team. Other members of your health care team include, but may not be limited to:

DOCTOR (PHYSICIAN)

As the leader of your health care team, your doctor is an expert in the field of hematology and blood and marrow stem cell transplantation. This is a field that focuses on providing patients with care that is the most advanced possible. His/her skill is balanced by compassion and concern for your emotional and physical needs.

NURSE PRACTITIONER/PHYSICIAN ASSISTANT

The nurse practitioner (NP) or physician assistant (PA) of the hematology/HCT team is a clinician who has had additional advanced training in hematology and blood and marrow transplantation. The NP or PA makes daily rounds with your health care team and helps to manage daily needs in collaboration with your doctor.

The NP or PA have been trained to perform some or all of the following procedures: bone marrow harvests, bone marrow aspirations, bone marrow biopsies, lumbar punctures and skin biopsies. The NP or PA works with individual doctors and will be available to provide care for you in the inpatient and outpatient setting.

NURSE COORDINATOR

Your nurse coordinator will play a leading role in preparing you for your transplant. He/she is an expert in cancer therapy and is responsible for coordinating tests/procedures that will take place before, during, and after your transplant. In most cases, your nurse coordinator will be involved in your first evaluation process and will help to answer any questions you may have.

NURSE

City of Hope has a large staff of experienced and dedicated nurses. They are specialists in all areas of patient care and will work to make you as comfortable as possible during your hospital stay. Over the course of your hospital stay, you will become familiar with various nurses who are highly trained in the care of pediatric and adult blood and marrow transplantation patients. These nurses work under the guidance of your doctor and work closely with all the members of the transplant team.

CLINICAL SOCIAL WORKER

Clinical social workers are an important part of your health care team who are available to meet with you throughout your care. We know that stress and challenges often can occur with a serious or long-term illness for both patients and loved ones. During your treatment, a clinical social worker is available to support you and your support systems emotional and social well-being.

Your clinical social worker will be able to answer any nonmedical questions you may have, and provide guidance to help get to your questions answered. This can include counseling, financial resource referrals, community resource referrals and support group information.

Clinical social workers can assist with improving communication and coordinating family meetings. This provides opportunities to meet with health care team members and discuss your medical care, goals and values for both patients and loved ones.

PSYCHIATRY

Psychiatric services are available to help maximize quality of life by helping patients deal with the psychiatric challenges that may arise during a cancer diagnosis and treatment. Psychiatrists help with medication management of anxiety, depression and psychiatric symptoms. Please notify your health care team if you would like to speak with a psychiatrist.

PSYCHOLOGY

Psychologists play a key role in helping you with the emotional, psychological and behavioral challenges that may arise during cancer diagnosis and treatment. Psychologists help reduce the impact of these challenges of coping and the ability to actively participate in care. Please speak with your health care team if you are struggling with any of these concerns and would like to speak with a psychologist.

CASE MANAGER

The case manager, often called “discharge planner,” coordinates home care services you may need after discharge from the hospital. Your case manager works closely with your doctor to create a treatment plan that meets all of your health care needs and to assure that you safely transition from hospital to home.

DIETITIAN

Dietitians will be available to assess your eating habits and then give you information regarding food and nutrition. Your dietitian will discuss important food safety guidelines to be followed during and after your hospital stay. Your dietitian will also help you with ongoing nutrition guidelines once you are ready to make the transition to home.

REHABILITATION TREATMENT TEAM

Because remaining active is a crucial part of your transplant process, City of Hope is a STAR Certified* institution and has specially trained oncology rehabilitation therapists who will work with you. Evidence suggests that exercise and activity help people recover more quickly, reduce stress and anxiety, reduce nausea, reduce fatigue, help with sleep, and reduce the risk of complications such as blood clots, pneumonia, weakness and depression. (See *“Top Ten Things We Want You to Know About Rehab”* handout.)

The therapists will work with you to develop a plan specific to your needs. (See Rehab Weekly Activity Schedule.) The goals of this plan are to help you maintain your physical, cognitive and leisure/social functioning to the best of your ability while undergoing the transplant, and to return to your prior level of engagement in your chosen and required activities as soon as possible following your discharge from the hospital.



The rehabilitation team is made of up physical therapists, occupational therapists and recreation therapists, each specializing in a particular part of your rehabilitation process. Physical therapists will review and monitor your physical condition and teach you appropriate exercise. They will work with you to set up a plan to help you stay as strong as possible throughout your treatment and show you how to change your plan as your tolerance for activity changes. When you are ready to be discharged from the hospital, they will help you design a plan to continue to build your strength and endurance on your road to recovery.

Occupational therapists will assess and monitor your ability to perform your activities of daily living (ADLs). ADLs can be activities as simple as dressing or bathing, or activities that are more complex such as computer use or event planning — anything that you find meaningful that will keep you active. They will work with you if you feel you are experiencing any chemotherapy-related cognitive impairments such as difficulty concentrating and/or forgetfulness, and they can help you with coping/anxiety reduction strategies as well. They will help you make a plan to address any of your concerns about responsibilities, roles, cognitive issues or coping strategies when you are ready to be discharged.

*oncologyrehabpartners.com

CHILD LIFE PROGRAM

The uncertainty of illness, treatment and procedures may cause fear and distress in children and their families. Child life specialists support children who are getting ready to receive procedures and treatment.

They do this by:

- Providing age-appropriate education
- Supportive activities and resources
- Building trusting relationships with pediatric patients by using techniques such as therapeutic and medical play

Child life specialists also provide services to pediatric patients and children of adult patients. Grandparents can also request child life specialists to help their grandchildren understand their illness and treatment.

They also provide support and education on end of life, grief and bereavement. Children and families who receive child life services are more confident and empowered in coping with their hospital events and a loved one's illness.



ACADEMIC ADVOCACY PROGRAM

School is an integral part of normal life for children, teens and young adults. Cancer or other serious illness can disrupt the sense of normalcy and connection it provides, beyond how it may affect their studies. The Academic Advocacy Program is designed around helping young patients continue their education. That helps them maintain that sense of normalcy through socialization and continued academic progress during treatment and recovery.

City of Hope's Academic Advocacy Program helps children, teens and young adults:

- Feel more normal and adjusted by keeping pace with their peers
- Increase self-esteem through opportunities for achievement
- Provide motivation to stay socially and mentally engaged
- Reduce depression and anxiety associated with treatment
- Have smooth transitions back to school after treatment

The Academic Advocacy Program provides services for all phases of education, including:

- Preschool
- Elementary school
- Middle/High school
- College
- Vocational studies

The Academic Advocacy Program helps to coordinate:

- Hospital tutoring
- Home instruction
- School reintegration
- Student and parent advocacy
- Special accommodations
- Neuropsychological testing
- Community resources and referrals



SPIRITUAL CARE TEAM

Many patients and their families rely on faith and/or spiritual beliefs to help them through the difficulties of cancer and its treatment. Spiritual care chaplains are trained to provide spiritual support and counseling for patients and families of all religions and beliefs. Please notify your health care team if you would like to speak with one of our chaplains.

PATIENT ADVOCATE

A patient representative is available to you during your stay at City of Hope and can help you find a satisfactory solution to any concerns or unmet needs you may have. Our goal is to ensure that your time at City of Hope is as safe, effective and comfortable as possible. If you or your family have any questions or concerns during your stay at City of Hope, you can reach your patient representative by calling the Patient Advocacy Office at **800-826-HOPE (4673), ext. 82285.**



"This guide helped us to simplify our life.
This way the only thing on our minds was
the transplant."

— BMT Survivor

Important Things to Know About

- Caregiver Role
- MyCityofHope Patient Portal
- Advance Directive
- Health Insurance, Financial