HEALTH AND STRESS

The Newsletter of
The American Institute of Stress

Number 12 1998

TENTH INTERNATIONAL MONTREUX CONGRESS ON STRESS

February 28 - March 5, 1999 Grand Excelsior Hôtel, Montreux, Switzerland

W. Ross Adey, M.D., Hans Selye Award Recipient. Plenary Sessions On Bioelectromagnetic And Resonance Therapies, The Epidemic Of Violence At Work and In Contemporary Society, Job Stress And Health In The Workplace, Post Traumatic Stress Disorder, Type A Behavior Update, Time, Stress And Creativity, And Much More. **Holistic Medicine Stress Reduction Day - March 6.** Exhibits, Poster Sessions.

HOW TO HELP YOURSELF TO HEALTH AND HEALING

Key Words: Internet health sites, Library services, HMO. PPO, PSO, ethical and legal rights of patients

The old admonition, "Physician, Heal Thyself" is increasingly being adopted by patients. In addition, many healthy individuals who want to stay that way, are avoiding their doctors' prescription to "Do as I say, not as I do", and are seeking advice on how to optimize their well being from other sources. In 1997, 43 percent of all Internet users, some 15.6 million people, searched for online health information. That's up from 38 percent and 13.8 million in 1996, and more than 30 million web health surfers are anticipated by the end of next year. The problem is there are at least 15,000 different sites specifically devoted to providing health information, and countless others offering some kind of advice or selling some product.

Determining which is the most authentic, up to date, or appropriate for your needs could take forever, since new ones keep cropping up almost daily. Unfortunately, this includes more and more unreliable sites, many of which are carefully crafted to project a patina of credibility and respectability. As a consequence, it is often difficult for consumers to distinguish between those that are reliable, and others based on conjecture and anecdotal reports or are commercially motivated. Books like *Webdoctor: Finding the Best Health Care Online,* are apt to be out of date by the time they appear.

Women's health, cancer and heart disease are popular topics, but Alternative Medicine is the most searched for health category. It accounts for 11 percent of all Web medical inquiries, but trying to identify authoritative information in this area is a particular problem, especially when it comes to extravagant claims for nutritional supplements and diets. Services like Tuft's Nutrition Navigator, which regularly review such sites can be useful in this regard. There are also watchdog groups devoted to exposing what is perceived to be quackery or outright fraud, especially for devices making immoderate medical claims.

ALSO INCLUDED IN THIS ISSUE

Health and Stress: The Newsletter of The American Institute of Stress is published monthly. Annual subscription rate $35.00 (U.S.), $45.00 (Foreign).

HEALTH AND STRESS
The Newsletter of
The American Institute of Stress

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What's Hot?

At the Department of Health and Human Services' Healthfinder site, a section called "Hot Topics" is updated monthly to reflect the 25 subjects that generate the highest volume of user traffic, and recently ran the gamut from adoption to sexually transmitted diseases. Prevention advice is particularly popular. Allergy and asthma sufferers visit the American Academy of Allergy, and Asthma and Immunology sites to check pollen counts and determine the best times to exercise. The Center for Disease Control and Prevention's travel section will indicate if a course of anti-malaria drugs or yellow fever vaccine is currently advised for a trip to Africa or Asia.

Since credentials may be hard to check in cyberspace, people tend to turn to free government resources for their health information, and with close to 900,000 visitors a month, the National Institutes of Health has more hits than any other health information site. Other comprehensive services which are readily available include the National Cancer Institute's clinical trial database CancerNet, and the National Library of Medicine's free access to Medline, a database of more than 9 million abstracts culled from 4,000 journals that can be accessed by subject, author, or source. It offers separate databases to search for information on AIDS and cancer.

The Health and Human Services Healthfinder site was established in 1997 to help people find reliable information on the Web. It served more than 1.7 million visitors its first year, and has a particular focus on how to attain and maintain good health. A new section called "Smart Choices," offers guidance on how to get healthy, stay healthy, and deal with chronic disease; how to locate good doctors and hospitals; how to report fraud and other complaints; and how to find reliable health information on the Internet. A links page called "Just for You" offers its top picks for consumers based on age and ethnicity. More FAQ (Frequently Asked Questions) on popular topics helps make it easier for less experienced users to organize their searches. Usage is rising at nearly 15 percent a month, and in the past year, Healthfinder's index of carefully reviewed reliable resources has quadrupled in size to more than 3,200 links! Also high on the list of trustworthy sites are those that represent well known academic institutions and non-commercial professional organizations,with gov,.org, or edu suffixes. Others that seem authentic, may be surreptitiously trying to promote products or services.

Support, Self-Help And Chat Groups

People suffering from disorders that are rare or have failed to respond to conventional treatment can also access chat groups and bulletin boards that share personal experiences, provide support, and post information on potentially new therapies. There are numerous accounts attesting to the remarkable results this type of interaction has achieved, one example being the following compelling story which attracted considerable national and global media attention and public participation.

In October 1997, Yongxin Deng, a 31 year old doctoral candidate from China studying soil science in Australia, received news that his apparently healthy 3 year old son, Shao-Shao, 5500 miles away, had just been diagnosed with a rare and usually fatal cardiac condition. Local doctors told his wife that only one ventricle was pumping, which was causing lethal pulmonary hypertension, and that they had no treatment available for this. Although he had limited Internet experience, Deng thought that the Web might be the best place to ask for information and assistance on what to do.

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Using his University's computer, he typed an e-mail message explaining the situation, and pleading to "kind people all over the world for any help or information." Since he didn't know where to direct this, he posted copies on several support and chat groups that could conceivably be sympathetic to his plight. A Swedish human rights activist copied the message onto his Web page, where it was picked up by Mary Ann Wehland, a mother in Oregon whose own son had already undergone three surgical procedures for a cardiac deformation. She sent a message back that she would help in any way she could, and that "The world is too rich to let this kid die without a fight." She also contacted the PDHeart List, an Internet support group for parents of children with congenital heart disease. Within weeks, hundreds of messages poured in also offering assistance, but little practical advice about what he could do.

The little boy's lips turned blue, indicating a worsening of his condition, and the doctors explained that although China had nothing to offer, U.S. pediatric cardiac surgeons had operated on a few similar cases with promising results. After contacting numerous hospitals here, tentative commitments were obtained from several specialists who agreed to provide free consultation, but would first require certain tests, and especially cardiac catheterization, to assess the degree of damage. This could only be done in a Beijing hospital specializing in cardiovascular surgery that already had a lengthy waiting list for other emergency patients.

Frustrated, Mary Ann contacted a pediatric cardiologist at UCLA's Children's Hospital who had seen hundreds of "inoperable" kids from foreign countries thrive after appropriate treatment. He agreed to examine the child and arrange for catheterization if he could be brought to Los Angeles. Deng obtained the required visas, and with his life savings and contributions from family and friends, was able to raise almost $2000 to cover the airfare. However, there was no way he could possibly pay for months of food, lodging, and expensive medical procedures once they got here. With his son's deteriorating condition, things looked hopeless. and Mary Ann again posted an e-mail with a picture of Shao-Shao on the PDHeart List, explaining the situation, and asking for volunteers to host the Deng family and to try to raise funds.

Brenda Isaacs-Booth, a Los Angeles actress whose 20 month old son had just recovered from two open heart surgeries, came to the rescue, and within days, raised $6500. Another mother in Michigan sent in $1000, contributions came in from all over the globe, and the Dengs finally arrived in Los Angeles on January 30, 1998.

The catheterization and echocardiogram results were not good, since they showed that the blood pressure in the lungs was too high for the surgical procedure that was required. However, the cardiac surgeon who had operated on Brenda's son thought that a preliminary surgical intervention to reduce this might make it possible to perform subsequent corrective procedures to reroute the flow of blood. Unfortunately, only $1000 was now available, and even with fees cut to the bone, the cost of subsequent surgeries would be more than $100,000. The actress contacted the Los Angeles Times, whose subsequent article triggered a national response, and a segment on NBC's "Today" morning news program. One of the viewers was Frederic Rosen, CEO of Ticketmaster, who wrote a $25,000 check, and convinced his friend, Los Angeles mayor Richard Riordan to match it. A contribution from an anonymous donor in New York, and others from around the world increased the available funds to $110,000.

On April 14, the preliminary procedure to reduce the lung damage by placing a band on the pulmonary artery was performed, and the little boy's condition seemed to stabilize following this and medications. An elderly lady in Santa Monica offered her home, and the Dengs later moved into a much closer guest house owned by a single mother who had adopted a four year old girl from China, so that Shao-Shao now had a playmate. His English improved remarkably, he gained weight, had more energy, and was able to undergo definitive reconstructive cardiac surgery on July 22. He started preschool in September, and although he has continued to thrive, a repeat echocardiogram showed a leaky valve, which may require repair. Hopefully, this can be delayed until next spring.

A chronological account and other interesting facets of this heartwarming story, as well as periodic updates on Shao-Shao's condition can be found on Brenda's Web page (http://members.tripod,com/~Binkygirl/China). (*Continued on Page 4*)

In a story which is much more typical of self-help rewards, the Internet certainly gave one 60 year old wman a new lease on life. She had suffered from severe rheumatoid arthritis since the age of 18. Despite replacements for both knees and an elbow, she continued to suffer pain and additional joint destruction that was not responsive to any medication. She learned from a Web search that some studies had shown that treatment with the antibiotic minocycline could help to relieve joint pain and swelling, and had apparently stopped or slowed the progression of the disease in certain patients when everything else had failed. She showed the printouts to her physician, and although the treatment was controversial, he agreed to try it, with amazing results. Three years later it is still working, she now pursues an active life style that includes regular swimming and teaching, and credits the Web entirely for her new found health.

At a recent Internet Health Day Conference, specific chat and special interest groups that provided information and interaction were confirmed as one of the best services available to the public on the Web. Numerous studies have shown that such social support groups can have powerful healing effects, and as one keynote speaker noted "Anecdotal evidence is starting to suggest that electronic versions of support groups may be even better." For example, one patient undergoing radiation and chemotherapy sailed through the treatment because a support group told him what to expect every step of the way. Depression groups are particularly popular and effective. However, former Surgeon General, Dr. C. Everett Koop, whose first commercial venture, Dr. Koop's Community had 2 million hits in the first few months after it was unveiled last summer, cautioned that on-line searches and chat rooms should be used to supplement physician visits, not replace them. "Seemingly credible health information can be buried on what by all appearances is an authoritative site".

The Web is particularly useful when a new drug is prescribed. Simply typing in its name in Medscape, (www.medscape.com) a physician oriented site, will tell you all you want to know about efficacy, suggested dosage, side effects, contraindications, and potentially dangerous drug or food interactions.

Where And When Should You Surf?

There are some sites, such as Reuters (www.reutershealth.com) that provide daily information on the latest health research in separate sections directed to patients and physicians. Each selection also contains a direct link to other relevant news reports. In addition, you can also search their archives section for previous reports on any subject that may have appeared up to a year or more previously. Health Front Page, (www.msnbc.com/news/health_front.asp), a service of MSNBC also provides daily information on the latest health news, with links to articles on similar topics. Mayo Clinic's Health Oasis (oasis@mayo.edu) has an excellent library, and will send you a free weekly e-mail on recent developments.

Some of the most popular and reliable sites are the American Medical Association (www.ama-assn.org) which is updated daily, Centers for Disease Control and Prevention (www.cdc.gov) which provides the latest immunization recommendations here and abroad, and other governmental agencies, which have a wealth of information on their activities and ongoing research. Among the most popular are the U.S. Department of Health and Human Services (www.os.dhhs.gov), National Library of Medicine (www.nlm.nih.gov), Food and Drug Administration (www.fda.gov), and National Institutes of Health (www.nih.gov). The American Cancer Society (www.cancer.org) offers comprehensive information on all malignancies, or if you are interested in breast cancer specifically, you can go directly to (www.cancer.org/bcr/report.html).

The American Academy of Pediatrics (www.aap.org) will answer any question you have concerning children's health. The March of Dimes (www.modtimes.org) provides the latest findings on the disorders they support with research funding, and the list goes on and on. Some health maintenance and managed care organizations, like Cigna (www.cigna.com/healthcare), also provide general health information, as well as assistance in determining how to take maximum advantage of the benefits available to their members. As will be seen, taking advantage of this may save you a great deal of time and money, and reduce your stress levels when dealing with the vicissitudes of managed care. (*Continued on Page 5*)

One of the best on-line medical resources available promises to be emedicine.com, the first installment of which was introduced in November 1998. Its thousands of pages were written by 400 various specialists who concentrated on what they perceived to be the most important common problems confronting emergency room physicians. Within a year, other editions will be devoted to dermatology and other specialties. Most reliable health information sites avoid recommending specific treatments because of medical and legal concerns, but this on-line textbook lists specific drugs and dosages, suggested diagnostic tests, and contains photographs and drawings of the disorder. You can also perform a search on signs and symptoms that generates a ranking of the disorders most likely to be the correct diagnosis.

Some watchdog groups question the motives of a textbook funded by advertising from drug companies, although this does not appear to have compromised the integrity or objectivity of this and other sites provided by academic and non profit health organizations. Someone has to foot the bill, and the subliminal association of a pharmaceutical product with an authoritative text apparently has significant promotional value, since it might imply endorsement regardless of disclaimers to the contrary.

Things will undoubtedly heat up further, as manufacturers of drugs and medical products struggle to gain a toehold in this increasingly popular arena, since it may prove to be much more cost effective than direct media advertising. Sixty percent of physicians now report that patients come to them armed with Internet information about their condition. Despite the growing popularity of health on-line, not all doctors are comfortable with these increasingly sophisticated and proactive patients pursuing matters on their own. Some don't want to spend the considerable time that may be required to debunk bad information, or explain why it is inappropriate and purely speculative. Others are simply uncomfortable about the loss of control that results from patients accessing medical material, whether it is good or bad. Little more than half of doctors surveyed believed that the Internet was beneficial for their patients, despite the fact that the vast majority admitted it was helpful to them.

Helpful Hints For Novices And Others

The problem with the Internet is that so much information is available, it's impossible to access everything to make certain that you are not missing something that might be important. And once you find exactly what you want, how can you determine if it is accurate? The following tips may be useful to help you navigate through an increasingly labyrinthine maze of confusing and conflicting claims .

- Check to see if the information comes from a reliable source, such as a well-known hospital or reputable health organization.
- The source of the material should always be identified, along with appropriate affiliations. A contact name and phone number is a real plus.
- Try to determine if the site has an editorial board and peer review process to insure credibility, and that relevant copyright details are listed.
- Check for dates to be sure the information is current, and recently reported side effects and precautions for drugs are included.
- Beware of sites that promote their own products or tout themselves as the sole or best source of information on anything.
- Make certain that any sponsorship, advertising, underwriting, commercial funding arrangements or potential conflicts of interest are thoroughly and clearly explained.
- Check to see if the site has won any awards from credible credentialing organizations. While the lack of this does not detract from its possible value, such endorsements are reassuring, but only if they come from reliable sources, since many are self serving.
- Don't be influenced by links to a reputable organization in an attempt to imply a similar degree of credibility. Although permission is usually requested, there is little to prevent a Web site providing a link to any other location.
- Be suspicious of any physician or service offering a diagnosis and treatment recommendations, unless you can validate who stands behind it and who the Webmaster represents.
- Always consult your physician before acting on any information you obtain on the Web. It may very well be accurate, but might not be appropriate for your particular problem.

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Accessing health information on the Internet is really surprisingly simple. Just going to any popular search engine like Yahoo, Alta Vista, Infoseek, Excite, or Hotbot and typing in what you want will usually take you to the most appropriate sites. Ready access is probably the major reason consumers go on line, since it's a lot easier to surf the Web, than wade through outdated texts in the Library. But what about people who are not computer literate, or don't have access to a computer that can go on line? Many in this category are older individuals who could profit the most from the free health information readily available on line. Almost every Public Library offers free Internet connection, and have personnel that can assist with your search, quickly teach you how to proceed on your own, and print out the results of your efforts.

In addition, most usually have on line access to EBSCO and similar services that allow you to search numerous periodicals and major newspapers for abstracts dealing with health related topics that contain different and more recent material from that available on the Web. In larger facilities, the entire article is often available on microfiche that can be printed out for a small fee. If you go to the Library, it is best to do so during the morning or early afternoon to avoid the crush of students standing in line to get Internet help for their homework assignments. It's also much more likely that experienced research librarians will be available for assistance and to answer any questions. However, after you get the information you want, it may be difficult to implement any changes or to try a promising new treatment without cooperation from your doctor, and more importantly, your insurance provider.

How To Manage Managed Care

Years ago, things were relatively simple. If medical care was required, you could go to any physician you wanted to, including a specialist. Since patients often personally paid for this, as well as any prescriptions, tests, or consultations that might be recommended, their physicians were more cautious about suggesting things that were expensive unless they were absolutely indicated. Only the physician determined what medications or tests the patient should receive, whether admission to a hospital was necessary, and for how long.

There was also much more privacy and confidentiality. Much of this has changed drastically with the advent of managed health care plans. These include an alphabet soup of HMO's (Health Maintenance Organization), PPO's (Preferred Provider Organization) and PSO's (Provider Sponsored Organizations), which are networks of doctors who contract with insurance companies or large corporations, and others. The presumed advantage is that such managed care plans reduce expenses for patients because of better buying power and increased efficiency. However, many feel their increasing focus on cost containment has been at the expense of quality and personalized care.

Today, physicians are lumped in with a variety of other health care professionals referred to as providers, and patients are similarly commercialized as consumers. In many instances, the HMO determines which providers can be utilized, what medications and tests are paid for, whether hospitalization will be allowed and for how long, and other details that were formerly decided by physicians and patients acting in concert. The rules and regulations also vary for each plan, making it difficult for providers who belong to several to keep up with these differences, as well as the frequent changes that keep cropping up in each one.

In most of these, you must first select a primary care physician (PCP) who belongs to the plan, and who also serves as a "gatekeeper", for referral to any specialist in the system. In certain plans, this is valid only for a specified number of visits over a limited amount of time. If your PCP thinks additional services are needed, prior approval from the managed care program must be documented, and blood tests, X-rays and imaging procedures are required to be performed by approved providers.

You may not have a choice of plans, although some employers are required to offer more than one option for eligible workers, and those who pay for their own health insurance can choose their own HMO. Most Medicare beneficiaries can select from several, and this will increase with the new Medicare + Choice program. Picking a plan that best fits your needs can be tricky, and it is essential to scrutinize the benefits section, and to check with your provider and primary care physician if you have any questions. (*Continued on Page 7*)

Some of these questions that need to be answered before making a final decision include:

- Are your current doctors members of the plan or is there any provision to continue to use them with a co-payment? What are the backgrounds and qualifications of physicians who participate in the plan? Does the primary care physician you have selected accept new patients?
- What percentage of specialists in the plan are board-certified and how difficult is it to obtain a consultation? In general, a referral is required from your "gatekeeper" primary care physician, but in many instances, if successive visits are required, approval must be again be obtained, and your physician may have to justify the need for this before the HMO will grant authorization.
- Are primary care physicians paid by salary, fee for service, or do they receive a stipulated monthly sum for every patient on their roster, regardless of whether they are seen? Under such latter capitation arrangements, there may be an incentive to limit office visits so that more income can be derived from fee for service patients. In some contracts. the costs of specialist visits are deducted from the gatekeeper's capitation income, which can also affect referral decisions.
- What services or treatments are not covered? While "experimental" or "investigational" treatments are almost always excluded, there is a wide degree of latitude in defining these, so you need to be as specific as possible. Bone marrow transplantation for breast cancer is accepted by some but not others, and there is considerable variation with respect to acupuncture, chiropractic, and even physical therapy services. What is the plan's policy on preventive and rehabilitative measures? Are child immunization, flu shots, or Pneumovax covered? How much and what kind of prenatal care, or cardiac rehabilitation after a heart attack is provided for? Managed care programs vary tremendously with respect to coverage, especially when it comes to new drugs like Viagra. Some won't pay for this, others reimburse completely for 1, 2, or 4 tablets a month for specific indications, while a few offer a co-payment clause. The same is true for new infertility procedures and cancer medications, as well as alternative services like chiropractic and acupuncture.
- What emergency services are covered? Some plans suggest that enrollees call their own emergency number rather than 911, while others advise getting to the nearest emergency room as fast as possible, but won't pay if it is subsequently determined that this was not necessary. But how can a lay person tell whether sudden or increasing abdominal and chest discomfort requires immediate attention? Over thirty states have now enacted legislation mandating that HMO's cover all such visits under a "prudent layperson" rule that provides reasonable protection, and you should determine your plan's position in dealing with this dilemma.
- How does the HMO provide for prescription drugs, and which ones are specifically excluded? Most require some sort of co-payment for each medication included in their formulary, and specify the pharmacy, or provide for mail order services to a specific facility for long term needs. In general, only generic drugs are included if they are available, and you may have to pay a hefty price if you or your physician insists on a name brand because substitution is not advisable. These formularies differ for each HMO, and may not include medications you require, and it is important to determine whether they will provide reimbursement for prescriptions not included in its list, and what this entails. Certain plans will only reimburse you after you have spent more than $500 in a one year period. If you know that it is likely that you will be taking generic or name brand drugs for an extended period of time, it's a good idea to determine if they are covered, and if not, what the additional costs will total.
- What happens if you are outside the area of coverage and need medical attention? Emergencies are usually covered, but many HMO's make a distinction between these and "urgent care", which does not need immediate attention, and requires prior approval to obtain reimbursement.

Read your benefits section carefully, particularly with respect to the above items, to avoid some of the following horror stories of managed care.

Some Representative Horror Stories

It might be assumed that the best HMOs were those with physicians who were readily accessible, and provided superior care, However, in many instances, medical decisions are made by others based on arbitrary guidelines, and participating doctors are restricted in what they can do. A recent survey of 766 found that the vast majority felt pressured to see more patients and to limit consultations, and defections are increasing. Many have economic incentives that also cause them to treat subscribers differently than their fee for service patients.,

For example, a female patient complained of abdominal pain and rectal bleeding, and asked to see a specialist. Her doctor did not do a rectal exam or sigmoidoscopy, but ordered an ultrasound study and prescribed a pain killer. She did not improve, and after requesting a referral from her doctor five more times, was finally referred to a gastroenterologist. He found that she had advanced cancer of the colon, and she died 18 months later. It may be relevant that her doctor was on a capitation plan that paid him $26.94 a month per patient to include treatment and specialist care, with the provision that he had to personally pay the first $5000 for referral costs.

Another was told by her primary care physician that tests suggested she was suffering from kidney failure, and he immediately referred her to a specialist. Her HMO refused approval, and although her condition steadily deteriorated, denied further requests for almost two years, until she and her doctor vigorously complained. When eventually seen, the consultant confirmed severe renal failure and the need for dialysis the rest of her life. She was awarded one million dollars, but only after lengthy arbitration.

A mother took her six month old son to her HMO where he was given a medication for an upper respiratory infection. However, his conditioned worsened, and by 4 A.M., his temperature was over 104°, he was vomiting and had difficulty breathing. She called the HMO's emergency number and was told to take him to their contract hospital 40 miles away. On the way, the infant lost consciousness and they detoured to the nearest hospital where he was found to be in cardiac arrest. After revival in the emergency room, he was immediately sent by ambulance to the HMO hospital, but permanent damage required amputation of both hands and partial amputation of his legs. The family sued, but their $45 million award was appealed, and they settled for an undisclosed amount.

A middle aged man experienced severe chest pain and numbness in his left arm - common symptoms of a heart attack. His wife called the HMO hotline and was told to give him an antacid to see if this would provide relief. She then received a subsequent call instructing her to take him to the participating hospital 16 miles away, but before she was able to get him in the car he stopped breathing. The wife called 911, but paramedics could not revive him. HMOs are required to pay for any emergency care under the "prudent layperson" rule in 33 states.

The above disasters are from some of the largest and most reputable managed care plans, and are hardly rare. You can help to avoid such problems and many minor glitches if you know your rights and follow the advice on the previous page, Hospitals are also complaining as HMOs feel the crunch of close competition and rising costs. Despite legislation requiring payment of "clean claims" within 45 days, New York State just reported an alarming increase in violations and abuses, with some plans more than 80 days in arrears. As prices for drugs and medical services continue to skyrocket, things will only get worse, so stay tuned.

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ISSN # 1089-148X

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The Newsletter of
The American Institute of Stress
124 Park Ave., Yonkers, New York 10703

TENTH INTERNATIONAL MONTREUX
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