

Amplified Musculoskeletal Pain (AMP)

A Guide for Families

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What is Amplified Musculoskeletal Pain?

Amplified Musculoskeletal Pain (AMP) is a very painful medical condition. It frequently affects a limb (a foot or leg more commonly than a hand or arm), but can cause pain anywhere on the body. In fact, children can have pain throughout most or all of their bodies. Most children with AMP have constant pain, although there are children who experience intermittent attacks of pain followed by periods without pain. We also treat children with disabling amplified abdominal or chest pain that is not musculoskeletal pain in the strict sense. The pain all these children experience, however, is much more intense than one would normally expect because the pain signal is amplified.

What forms and other names does amplified musculoskeletal pain go by?

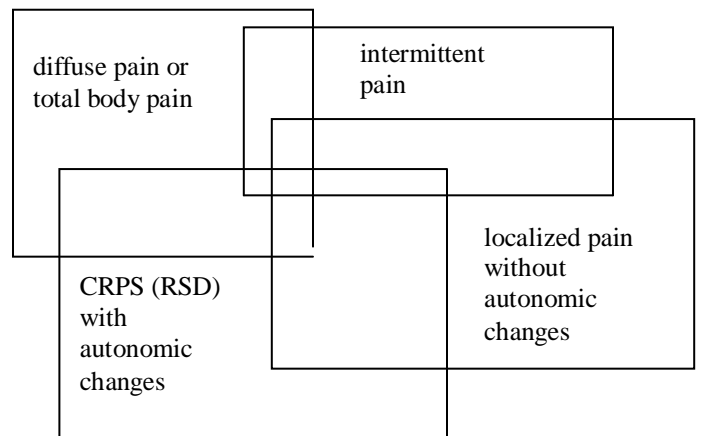
There are various patterns or kinds of amplified musculoskeletal pain that are called a variety of names. We prefer the term amplified musculoskeletal pain since it refers to the fact that the body takes a mild pain signal and makes it very painful, similar to when a guitar amplifier takes a soft sound and makes it very loud. Most of the names given to this condition are related to where the pain is or to changes in the skin temperature and color (autonomic changes). Some of the many names used include reflex sympathetic dystrophy (RSD), reflex neurovascular dystrophy (RND), complex regional pain syndrome types I and II (CRPS I & II), causalgia, Sudeck atrophy, shoulder-hand syndrome, localized or diffuse idiopathic musculoskeletal pain, neuropathic pain, central sensitization pain syndrome, fibromyalgia, algodystrophy, psychogenic pain

or psychosomatic pain. Information in the literature and on the Internet is quite confusing; most of it applies to adults with specific syndromes, especially the terms fibromyalgia and reflex sympathetic dystrophy. The term sympathetic can be mistakenly construed to suggest these children are just looking for sympathy.

Children are different than adults in their presentation, the response to treatment and the long-term prognosis; children fare much better. Therefore, we avoid using the terms RSD or fibromyalgia except for research purposes.

Various forms of AMP can coexist in the same child or, if there is a reoccurrence, the second form may be different from the first form. A pictorial representation of the overlapping nature of the forms of AMP is shown below:

Forms of AMP – These forms overlap and a child may have one or more at the same time or have a reoccurrence with a different form than the original presentation. Autonomic changes include coldness, blueness, swelling or perspiration.



What form of amplified musculoskeletal pain does my child have?

AMP has multiple manifestations and each form can be named separately as shown above. We use the term amplified musculoskeletal pain (AMP) to encompass the spectrum of these pain syndromes. We use the more specific terms in our research and for logistical purposes. We will discuss your child's specific AMP diagnoses with you and your child after

the evaluation. We want to emphasize that all amplified pain is severely painful and we are not sure one type hurts any differently or more than another.

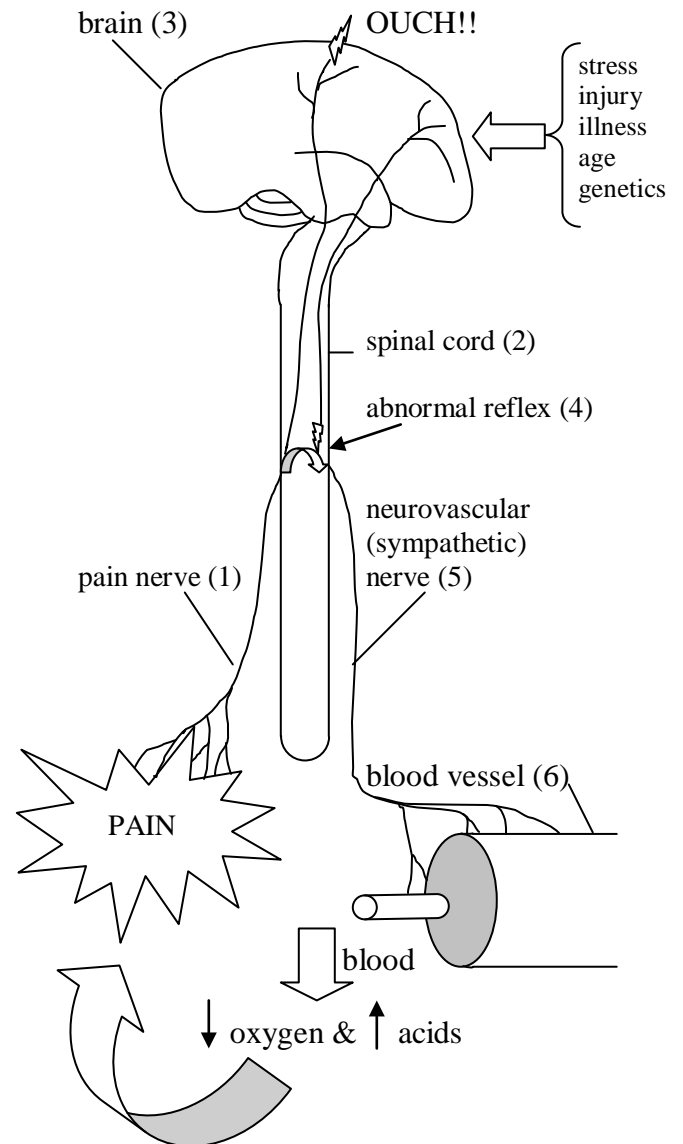
How is the pain signal amplified?

First, look at the figure to see how we normally feel pain. Usually pain is in response to tissue damage, such as stepping on a tack. The damage sends a signal through the pain nerve (1) to the spinal cord (2). The signal is then transferred up to the brain (3). The brain then recognizes the signal as being painful. In AMP there is an abnormal short circuit in the spinal cord (4). Therefore, the pain signal not only travels up to the brain, but also goes to the neurovascular (or autonomic – fight or flight) nerves (5) that control blood flow through the blood vessels (6). These nerves cause the blood vessels to constrict thus decreasing blood flow. The decreased blood flow deprives the skin, muscles, and bones of oxygen and leads to a build-up of acid waste products such as lactic acid. This lack of oxygen and acid build-up causes pain. This new pain signal also goes across the abnormal reflex and causes a further decrease in blood flow, leading to more pain. Thus, the pain is greatly amplified through this vicious cycle.

At times, the part of the body with AMP will become cold, blue or purple, and even swollen due to the decreased blood flow. Although no test is specific for AMP, sometimes x-ray studies show osteoporosis, a bone scan may show decreased blood flow and an MRI can show bone or soft tissue edema and muscle wasting (atrophy). Rarely, the skin will become thick and waxy (dystrophic), a characteristic that gives reflex sympathetic dystrophy part of its name.

What causes the abnormal reflex?

There are 3 major reasons for the abnormal reflex: injury, illness, and psychological stress. There may be other reasons such as age, genetics, or hormones (80% of children with AMP are girls). More research needs to be done.



What kind of injuries lead to AMP?

The cause of AMP in approximately 10 - 20% of children is injury. The majority of children with post-traumatic AMP have a significant specific injury such as a broken bone, crushing or piercing injury, or surgery. The symptoms develop immediately or within a few weeks after the injury. Not uncommonly, as the injury begins to heal, the pain starts and then continues for weeks to months after the injury has fully healed. AMP can mimic previous pain experiences (e.g., feel like a broken bone, even if the bone has fully healed).

What kind of illnesses lead to AMP?

Illness is an infrequent cause of AMP. Most commonly it is seen in conjunction with

inflammatory illnesses of the musculoskeletal system such as arthritis, tendinitis, myositis or enthesitis. Other illnesses may be the initial cause of pain; most are infections such as mononucleosis, influenza, or gastroenteritis. Constipation can lead to amplified abdominal pain.

What kind of psychological stresses lead to AMP?

In at least 80% of children with AMP, psychological factors seem to play a role. There is a whole host of possible stresses that may play a role in causing (or perpetuating) AMP. Notably, we use the term “stress” very broadly. Stressors can be positive or negative, big or small, and can include not just events, but feelings and personality styles. Many of the stressors that impact AMP are normal, everyday stressors that all children face; unfortunately children with AMP tend to experience these stressors in their bodies as pain, while other children may show their stress in other ways. One major stressor we see in many children is the psychological consequence of having such severe pain. This frequently is due to others not understanding the nature of the pain (many friends, teachers and family members do not believe the pain is as intense as it is) and also having a delay in diagnosis and multiple failed therapies. It is very frustrating. Additionally, all change is stressful, even a change for the good. Feelings such as fear, worry and shyness are stressful as are the stresses of the events occurring in the world. The most common stresses we see in these children are those that arise from family and school issues. Many families are undergoing changes such as an older sibling leaving home, new jobs, or marital issues. School is more demanding; peer pressure, social demands and social networking can be quite intense. Many children do not like conflict and have difficulty expressing their opinions, asserting their needs, or saying “no” for fear of upsetting others, which can also lead to stressful situations and experiences. Developmentally, most children with AMP are gaining more independence and responsibilities

and may be going through puberty, which also increases stress. Some children cope with stress by keeping it inside and this stress can lead to bodily symptoms including AMP.

Is the AMP all in my child’s head?

No, not at all. The pain is very real and very intense. Even in those children for whom psychological stress is a trigger or complicating factor, the decreased blood flow to the area of AMP causes the extreme body pain.

What are conversion symptoms?

Conversion symptoms occur when the subconscious emotional self causes nerve activity or inactivity. The classic example is a girl who suddenly goes blind after seeing her dog get run over by a car. In such a situation, the girl has no physical problems with her eyes or her brain; however, the stress of her experience disrupts the communication between her eyes and brain resulting in the experience of blindness, without true structural damage. She is truly blind in that her brain does not consciously process any visual information. Most children with AMP do not have such a dramatic event leading to their conversion symptoms. Conversion symptoms we commonly see involve involuntary spasms of the muscles (like a clenched fist or shaking (sometimes mistakenly called dystonia), dizziness, racing heart, fainting and lightheadedness (often called POTS (postural orthostatic tachycardia syndrome) or dysautonomia) non-epileptic events (or pseudoseizures), shortness of breath, memory problems, paralysis, numbness, coughing, urinary urgency or retention, inability to talk, and visual difficulties (e.g., unable to read but can see). Sometimes the conversion symptom is more of a problem than is the pain and is therefore best addressed in a treatment center with a focus on conversion rather than pain. We call all of these symptoms “conversion” so that there is no confusion with seizures, muscle or nerve damage, or illness. The vast majority of these symptoms need to be ignored since calling attention to them tends to make them worse. It is a subconscious process and needs to

be addressed by working hard in counseling. Physical and occupational therapy by skilled therapists can also be very helpful. Conversion symptoms that are very entrenched and hard to break generally bespeak the fact that stress is playing a large role and needs to be addressed before the conversion will resolve. Whether it is short or long-lived it is important to remember that conversion is subconscious and not voluntary. Up to 40% of children with AMP will have at least one conversion symptom.

Are there any laboratory tests to prove it is AMP?

No. Blood tests are normal unless there are other conditions present (for example, an infection can alter the blood counts and sedimentation rate). In some children a bone scan or MRI can show abnormalities that are very suggestive of AMP, but the results may be normal.

What can be done to help my child?

It is most important that someone with AMP begin to use his or her body in a normal way. The abnormal reflex is broken by intense physical and occupational therapy (PT/OT). Some children are able to do this on their own by exercising at home. Although it hurts to do the therapy, it does not cause damage, and some children are able to work through the pain. Many children will need to participate in an intense PT/OT hospital treatment program. It just hurts too much for them to do it on their own. The intense PT/OT program is usually a daily out-patient (day hospital) program but some require inpatient hospitalization. The children who need to be put in hospital include those who are severely incapacitated, have a chronic medical condition that requires closer monitoring during treatment, need to wean off certain medications, have marked pain behaviors such as night time screaming, or need a behavior modification program.

Our intense program affords each child 6 hours of daily PT and OT along with psychological evaluation and support through psychotherapy and creative art therapy. Other programs vary

depending on local resources. The following describes the different aspects of our program.

Phases of our program:

The intense PT/OT hospital treatment program is just the **first phase** of our program. Most children will be fully functional at the end of this phase but most will still have pain, though the pain usually has started to decrease by the time of discharge from the hospital. The **second phase** of the program is to maintain normal function (school, sports, chores, socializing) and continue to do a home exercise program with or without psychotherapeutic counseling (depending on the results of our evaluation). **It is during the second phase of the program that most children will resolve their pain.** The **third phase** of the program is to graduate from a formal home exercise program and to have normal function without pain.

Prior to or as part of the initial clinic evaluation, we do an evaluation to help determine if stress plays a role in your child's AMP. This involves filling out questionnaires and often talking to a psychologist. Our social worker will need your child's academic record and we may administer academic testing. After this evaluation we can give you more specific advice about how stress may be impacting your child's AMP and whether counseling is advisable. A few children need a behavior modification program. If we think your child needs this, it will be discussed with you in depth.

How long does the treatment program take?

The average length of treatment is 3 weeks for the first phase. Occasionally, a child will respond quickly and only need 1 or 2 weeks. Likewise, a few will require many weeks. The duration of treatment needed is impossible to predict until we see the rate of your child's progression once in the program. We decide discharge goals on a weekly basis during our team meeting and review them daily.

It is important to realize that **function comes back first**; normally the pain will take longer

to decrease. Some children will resolve their pain during the first phase of treatment but most will do so during the second phase; that is, once they are in school, maintaining normal function, and perhaps receiving counseling. The pain usually diminishes gradually over the ensuing month or two but rarely will take many months. There are a few children who will have pain for years but almost all who have gone through our program remain functional. It is not uncommon for the pain to increase at first or move or spread to different locations.

What will my child do during the first phase of treatment?

Your child will have an individualized PT/OT program designed specifically for him or her. It focuses on strengthening your child's total body and specifically on the areas of the body that are painful or do not function properly. If there are body areas that are painful to touch, these areas are desensitized with rubbing and massage. Physical and occupational therapists that are experts in AMP direct the program therapy. A home exercise program is part of the treatment, especially over the weekends. There will be scheduled appointments with the psychologist for the child and parents, patient support group, parent support group, art therapy, and music therapy.

Are parents allowed in the exercise sessions?

No, we have found it is best that parents not be present. Children often respond differently in a parent's presence. We find it important to help children gain confidence in their abilities to cope independently, as we emphasize their independence throughout their treatment. While your child is being treated we encourage parents and families go about their usual activities as much as possible.

Can parents eat lunch with their child?

Parents are allowed to have lunch with their child on the first day of admission only. After day one we want to closely simulate a school day, therefore, your child will have lunch daily with the other children in the hospital treatment program. Lunchtime also provides

opportunities for patients to socialize with and provide support to each other.

What about school?

School is put on hold during the program. Some children can benefit from homebound instruction during the evenings. We will contact the school to help the child reenter school with appropriate educational accommodations so that he or she will not be overly stressed and overworked. We will contact the school to obtain the child's academic records and other pertinent information. If indicated, we will do a few academic tests or a psychoeducational evaluation to ensure that your child's educational goals are appropriate. It is a treatment expectation that all children will return to school full time without physical accommodations for pain or conversion at the end of the intense first phase of the program. Children who benefit from academic accommodations due to a learning disability, attention deficit, or other learning need will keep such services. We do not typically encourage Cyberschool post-discharge.

What is music therapy?

Music therapy helps your child gain coping skills to help work through and decrease pain. It may help with sleeping. Methods of coping include music assisted relaxation techniques to promote positive mind/body connection through deep breathing, progressive muscle relaxation, imagery or mindfulness-based techniques. Music therapy promotes self-expression through music production, song-writing or lyric discussion. Your child will typically work individually, once per week and sometimes in lieu of free time, with a music therapist who has extensive experience working with children with amplified pain. There is a weekly music therapy group session and music assisted relaxation during one pool group.

What is art therapy?

Art therapy is another way to help your child express his or her feelings by using various art techniques with the guidance of a trained art therapist who has extensive experience with

children with amplified pain. Your child will typically participate in one individual art therapy session and one group art therapy session per week. The process of making art focuses on self expression, as a support while in the program, and helps teach healthy coping and wellness awareness.

What happens if my child gets sick or injured?

We will fully assess the nature of the illness or injury and treat it appropriately. We want to see your child even if he or she is thought too ill to participate in the program. Most of the time, we can continue the program with modifications. It is not uncommon for a child to have a minor injury and develop AMP in the injured area during the program. Very rarely a child is sick or injured to the point that they need to leave the program until the illness or injury resolves. Occasionally other issues (unable to cooperate, death in the family, severe depression or suicidal ideation) arise that require the child to leave the program early. Children who leave the program early can be readmitted once everyone is convinced it will be successful.

What if the pain spreads or goes to a new site while my child is in the intense PT/OT program?

It is not uncommon for the pain to spread to go to a new site while undergoing the intense PT/OT program. It frequently is a good sign when the pain moves since it means we have connected to the autonomic nervous system (e.g., one child with elbow pain developed knee pain as the elbow pain resolved, then ankle pain as the knees got better, then no pain). The therapists will alter the program to include the new areas of pain. Also itching occurs in many children as they get better. This itching is normal and does not need to be specifically treated.

Does the exercise program have to be done here?

The intense first phase of the program has to be done here (or in a similar center with therapists experienced in treating AMP). Children needing an intense PT/OT program are best

served by therapists who understand AMP. The type of therapy needed is different from what most physical and occupational therapists are taught. Most local therapists are not able to deliver the amount of therapy required. However, there are situations where we can work with a local therapist and, as stated above, not all children need the full 5-hour a day program. We are very supportive of having other therapists develop an expertise in treating children with AMP. More treatment centers need to be established so children can be adequately treated close to home and in a timely fashion. We can supply your physician and therapist with written descriptions of our exercise program. Resource material is available at www.childhoodrnd.org.

What do I tell others?

In simple terms you can explain that AMP is a medical problem involving the nerves going to the blood vessels. These nerves are overactive and cause the pain. The treatment is a special series of therapeutic exercises to retrain the nerves.

Are medicines used for the pain?

No. Most patients take no medication to treat AMP because it seems to hinder the retraining of the nerves. This includes herbs, vitamins and other complimentary treatments taken for pain. Also, medication frequently causes side effects in these children and has minimal, if any, benefit. Other pain such as menstrual cramps are treated as indicated but these, too, can become amplified as can any source of pain.

What about sleep?

Many children with AMP have difficulty getting to sleep, staying asleep, or both. Many people think that if we can improve their sleep, their pain will decrease, but that is not the case. Therefore, we do not treat sleep with medications since they usually do not help and can cause significant drowsiness and other side effects. We encourage good sleep hygiene, especially while children are in the intense PT/OT program. It is uncomfortable to be awake all night and most children start sleeping

better once they start the intense PT/OT program.

Sleep Hygiene:

1. No caffeine after noon; don't eat or drink much prior to going to bed
2. No TV, radio, phone or computer in the bedroom
3. Sleep alone in your own bed
4. All lights out
5. Comfortable temperature and bed
6. Create a structured bedtime routine that includes relaxation prior to going to bed
7. Go to bed and arise at the same time even on weekends and holidays
8. If you are not asleep 30-45 minutes after getting into bed, get up and do a quiet, boring activity, i.e., jigsaw puzzle
9. Do not disturb your parents – they cannot help you sleep.

How can I prevent AMP from happening again?

Your child is going to have illnesses, injuries, and psychological stress in the future. We do not suggest avoiding activities or situations that may involve stress or injury based on the fact your child had AMP. It is our goal that your child has learned how to work through these pains early on and has gained the coping skills to handle stress in a more constructive fashion. However, if your child starts to have excessive, increasing pain you should suspect AMP. Also, if the area is tender to very light touch, suspect AMP. Half of the children with a second flare of AMP will say that the pain feels just the same as the first time; however, half will say that it feels different. For example, AMP may be burning and tender to touch during one flare and achy without much tenderness during a second flare. Therefore, even if the pain feels different, it still may be AMP. If you suspect AMP, restart an exercise program. If it is tender to light touch, desensitization with rubbing and massage should begin. The majority of second flares occur within the first 6 months of the first episode. Therefore, when illness or injuries occur, be sure that the pain and disability is not

out of proportion to the illness or injury. With second episodes we are especially concerned that underlying stressors are playing a role and need to be reassessed and, if present, treated. Formal counseling can be of great help. It is important not to reinforce the sick role. When a child is hurt or in pain, the normal response is to give sympathy and make allowances such as not having the child make his or her bed if he or she has a broken arm. Children in chronic pain, especially AMP, either consciously or unconsciously, receive benefits, or secondary gain. This can take the form of missing school, increased parental attention, avoiding stressful social situations, getting out of sports, dance, music lessons, etc. Even though the child may truly enjoy these activities, it is still somewhat of a relief that he or she does not have to perform. We have children with AMP who have parents sleep with them, miss work to take care of them, and excuse the child from all chores and limitations. It is important for the family to stop enabling the pain and disability. We want to remove any secondary gains or reasons for the pain to linger, in order to help children get rid of their pain as quickly as possible. Frequently it is hard to recognize what is enabling and what is just normal caring. Sometimes having either the parents or family work with a counselor is helpful in this regard.

Do children come back to the intense PT/OT program for second treatments?

Yes. Unfortunately, some children will have relapses that require second treatments. It just hurts too much for them work through it without the support of an experienced team. Additionally, there are children who need to be more emotionally ready to get better before they can fully benefit from our program.

Vitamin C

An older woman who breaks her arm has a 10% chance of getting CRPS (RSD) in it but if she takes vitamin C for about 2 months after the break, her chance of getting CRPS drops to 2%. Likewise vitamin C reduces the occurrence of CRPS (RSD) after carpal tunnel surgery. Therefore, in our patients, we advise taking

vitamin C for 2 months after any significant trauma. If he or she has a scheduled surgery (such as wisdom teeth removal) we advise taking vitamin C for at least a month afterward and to start it 2 days before the procedure.

Why did it take so long to diagnose the AMP?

Early diagnosis may be difficult for several reasons:

1. Not all the AMP symptoms may be present at first but may evolve over time.
2. Urgent problems such as fractures or infections need to be ruled out first to be 100% sure before starting an exercise program.
3. Sometimes physicians will attribute pain to benign irregularities (e.g., a minor variance found during an endoscopy or colonoscopy) for lack of any other physical/test findings.
4. It may be hard to recognize since there is a wide spectrum of AMP so unless the doctor has seen a variety of children with AMP he or she may not recognize it.

Why does it take so long to get in to the AMP Program for treatment?

Unfortunately there are many children suffering with AMP that have waited a long time for a diagnosis and will need to wait further for treatment. Due to the time-intensive and individual nature of treatment, and the space needed to complete these physical activities, there is a limited number of treatment spots across the few programs that treat this condition. In our program, each child is treated individually and stays as long as clinically appropriate. Therefore, we cannot predict when slots will open up or how long your child will have to wait for treatment. While we understand that the wait is very frustrating and difficult, we try to treat each child fully and fairly, and cannot accommodate children into the program any faster than we have treatment slots available. We encourage all children and families to follow recommendations provided during clinic visits to help prepare for treatment while waiting to come into the program. Beginning psychological counseling during this

wait can also help enhance your child's coping ability and help begin to address areas of stress that may facilitate your child's treatment once he or she is admitted into the intensive program.

What is the long-term outcome?

There are few studies of long-term outcomes. In one study where the children were treated with an intense PT/OT program, 88% of the children were pain free and fully functioning after an average of five years. We find that children who have more difficulty becoming pain-free after treatment tend to minimize the role of stress in their lives and are reluctant to engage in the psychological components of treatment. Overall, the more fully children engage in all aspects of treatment, the better their prognoses.

If psychological stress is a cause of AMP, we have seen children subsequently develop a wide variety of other psychologically driven disorders such as anorexia nervosa, bulimia, other amplified pain syndromes (such as abdominal pain, headache, eye pain, sinus pain, tooth pain), an isolated conversion reaction (see above), and suicide attempts. If your child has any prolonged, unexplained pain or other symptoms, suspect an amplified pain or amplified symptom or conversion.

What is being done to find out more about AMP?

There are only a very few places doing research on children with AMP and The Children's Hospital of Philadelphia is one. You and your child may be asked to take part in a research project. Before participating in any research project, it will be fully explained to you and is always entirely voluntary. The care of your child is not dependent upon participating. Contributions toward research are always appreciated.

Website: www.childhoodrnd.org

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