Physician's Note - Symptom & Treatment Checklist

My patient _____ DoB _____ has a diagnosis of

(ICD-10-CM _____ and requires individualized supports and services that are similar to those of someone diagnosed with Prader-Willi syndrome (ICD-10-CM Q87.11). The following supports and services are necessary for the health and safety of the individual you are serving:

Check Box if Symptom Exists	Symptom Name	Symptom Description	Intervention/Medication/ Support	Additional/Specific Instructions
☐	Hyperphagia	PWS hyperphagia is a life-threatening, uncontrollable genetic drive to eat that is not satiated regardless of the quantity of food consumed. PWS hyperphagia includes preoccupations with food; food seeking, foraging; manipulation, sneaking, hiding, and hoarding food; and eating unusual food-related items (e.g. sticks of butter, pet food, mouthwash, rotten food taken from trash). PWS hyperphagia causes food-related anxiety that frequently results in dangerous behaviors (e.g. verbal aggression; physical aggression; elopement; burglary; theft; self-injury; lack of regard for personal safety). There is no learning to control PWS hyperphagia. Treatment consists of restricted access to food and continuous supervision. No currently known medication reduces or eliminates this life-threatening symptom. PWS hyperphagia has caused fatality from a single food gorging incident.	Frequently, very low calorie diets are needed to achieve or maintain a healthy weight (e.g., 800 – 1000 kcal/day if the patient is not treated with growth hormone). Adjust diet to patient requirements, following weight closely. Patient should be provided with a food secure environment that includes: • **Food should be locked at all times.** • Menus for breakfast, lunch, dinner, and snack should be posted (patient should be aware in advance of what meals/snacks will consistent of). • Meal/snacks should be consistently offered at the same time throughout the day, every day. • Adult supervision should be provided during all snack and meal times. • Registered dietician trained in PWS should provide specific outline/amounts/ types of food offered for meal plan.	• Patient should receive a maximum of _____ calories per day consisting of _____% Protein _____% Carb
☐	Anesthesia & Medication Sensitivity	Individuals with PWS can safely undergo anesthesia. Risks are related to their general health before the procedure. The majority of complications do not appear to come from general anesthesia, which is always closely monitored, but from poorly monitored conscious sedation.	Only a physician familiar with the patient and their individual medical needs should make medical decisions. Patients undergoing general anesthesia should be assessed by a pulmonologist first, probably with a sleep study, to see if they need CPAP/BiPAP afterwards. Coming out of general anesthesia takes longer so the gas passer should consider leaving them intubated longer and take their time to wake up. Observe overnight after general anesthesia, even for simple procedures, due to respiratory compromise and apnea, at least for children under 3 years old. After surgery, may need restraints to prevent the individual from pulling IVs, etc. or skin picking.	

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☐	Anxiety	Excessive, disproportionate worry or fear that is triggered by *any* stressor or frustration. Persons with PWS typically feel high levels of anxiety all the time.	Maladaptive, unwanted behaviors are often attempts to reduce the level of anxiety the individual is feeling. Implement PWS Behavior Management Protocols*. Psychotropic medication may be prescribed to reduce symptoms.	
☐	Apnea-Central	Breathing is impaired because the brain doesn't send proper signals to the muscles that control breathing.	Diagnosed by a Sleep Study. Use of continuous positive airway pressure (CPAP) or bilevel positive airway pressure (BPAP) at night.	
☐	Apnea-Obstructive	Breathing is impaired due to upper airway obstruction.	Diagnosed by a Sleep Study. Assess for need for adenotonsillectomy. Weight loss, use of continuous positive airway pressure (CPAP) or bilevel positive airway pressure (BPAP) at night.	
☐	Attentional Deficits	Difficulty sustaining attention to tasks, especially non-preferred tasks. Instability to sustain attention especially when food is accessible or on one's mind.	Continuous reminders to return to task. Psychotropic medications may be helpful. Removal of food from the environment.	
☐	Autism Spectrum	A neurological and developmental disorder that begins in early childhood and lasts throughout a person's life. It is a wide range (spectrum) of conditions characterized by challenges with social skills, repetitive behaviors, speech and non verbal communication.	Treatments include intensive sustained special education programs and behavior therapy early in life. Available approaches include: applied behavior analysis, structured teaching, speech and language therapy, social skills therapy and occupational therapy. Medications may be helpful for symptom management.	
☐	Behavior Management Deficits See also: • Autism Spectrum • Elopement • Lying and Confabulation • Repetitive Behavior • Self Injurious Behaviors • Skin Picking • Theft • Wandering	The PWS hyperphagia food drive underlies many food-related behavior problems but is not the sole reason for unwanted or maladaptive behaviors. Additional common symptoms include argumentative, stubborn and oppositional behaviors, impulsivity, inflexibility, obsessive and/or ritualistic behavior, high need for predictability and sameness, sensitivity to real or perceived stressors or frustrators, sedentary and slow moving, and aggressive verbal and physical behaviors.	Implementation of and adherence to PWS-specific behavior management strategies is essential. ABA treatment approaches used for persons with Autism often *increase* behavior problems in persons with PWS. Request PWS behavior management educational materials and/or training from the Prader-Willi California Foundation (PWCF) or the Prader-Willi Syndrome Association (USA).	
☐	Bone Mineral Deficiency	Reduced bone minerals due to decreased production of sex or growth hormones, hypotonia with decreased physical activity and deficient intake of calcium and vitamin D with calorie-restricted diets.	Increased sunlight exposure, nutritional therapy (vitamin D and calcium supplements), hormonal replacements (estrogen and testosterone), growth hormone therapy, and weight bearing resistance exercise.	

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☐	Cognitive Deficits	The patient's mental processes that lead to the acquisition of information and knowledge and drive how the patient understands and acts in the world. Areas of cognitive functioning include: • Attention • Decision making • Judgment • Language • Memory • Perception • Planning • Reasoning • Visuospatial • General fund of knowledge	Early intervention therapies including physical therapy, infant stimulation therapy, and growth hormone therapy initiated < age 2 years may improve cognitive functioning. Assessment of adequacy of vitamin and mineral intake by a dietician, and prescription of appropriate supplementation, is indicated. Supplements that may provide cognitive benefit but for which there are no controlled studies include Coenzyme Q-10, fish oil, certain B vitamins, and acetyl-L-carnitine.	
☐	Depression	Persistent sad, anxious, or "empty" mood. Feelings of hopelessness or pessimism. Feelings of guilt, worthlessness, or helplessness. Loss of interest or pleasure in hobbies or activities.	Traditional psychotherapies, such as Cognitive Behavior Therapy, may not be helpful due to lack of insight necessary for progress, and symptoms of confabulation (story-telling). Psychotropic medications may be necessary to decrease symptoms.	
☐	Developmental Delays	Lack of expected typical physiological development in childhood.	Early intervention therapies including physical therapy, occupational therapy, infant stimulation therapy, oral motor therapy, and speech and language therapy.	
☐	Diabetes Type II Mellitus	A group of diseases that result in too much sugar in the blood (high blood glucose).	Treat as in the general population. Diet compliance is a significant concern. Weight loss is important, and the diabetes may resolve with significant weight loss in obese patients. Monitor blood sugar levels and keep them at goal set by physician, and combination of diet, exercise and medication.	
☐	Edema	Swelling caused by excess fluid trapped in the body's tissues.	Treat underlying cause. Medication is often necessary.	
☐	Elopement	When the person leaves a setting without authorization when departure presents a threat to the safety of the patient or others. Elopement generally occurs when individual is in search of food.	Continuous monitoring. Alarms on all exits including windows and doors for people with a prior history of elopement.	
☐	Epilepsy	A neurological disorder in which nerve cell activity in the brain is disturbed causing seizures.	Treatment includes medications to control seizures. For some, the ketogenic diet can help, however this diet requires medical supervision.	
☐	Gastroparesis	Slow, delayed emptying stomach. Stomach distention, hard, bloated; reflux. Vomiting rarely occurs in persons with PWS.	Chronic condition. Serve smaller sized meals; provide cooked rather than raw vegetables; medication such as low dose metoclopramide or antibiotic.	

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☐	Growth Hormone Deficiency	A feature of PWS that causes short stature, small hands and feet, dysmorphic facial features, weaker muscle tone, low bone density and strength, reduced respiratory function, and slower metabolism.	Growth hormone therapy (GHT) is a standard of care for PWS. GHT may be prescribed based solely on the genetic diagnosis and growth pattern rather than the results of GH deficiency testing. Decisions about appropriate age to begin GHT and doses should be made by an experienced endocrinologist, with consultation from a PWS endocrine specialist when necessary. **Infants & Children**: When started in infancy or childhood GHT can improve height, weight, respiratory function, body mass, strength, agility, and may help with cognitive development. **Adulthood:** When prescribed in adulthood, GHT has shown positive results in areas of bone strengthening, leaner muscle mass, and increased energy. Dosing for adults is a low "maintenance" dose. Too high a dose after the growth plates close may cause acromegaly. Insurance companies may require GH stimulation test to prove GH deficiency.	
☐	Hypotonia See also "Muscle Tone"	Low muscle tone involving reduced muscle strength. Nearly all infants with PWS exhibit severe muscle weakness. Muscle tone improves with age but individuals never develop normal muscle strength and often fatigue easily.	Growth hormone therapy (GHT) can significantly improve hypotonia though it does not normalize muscle tone. GHT is generally recommended throughout the lifetime to reduce many PWS symptoms including hypotonia. Physical therapy is recommended during childhood and regular physical activity is recommended throughout the lifetime including strengthening exercises and activities.	
☐	Kyphosis See also "Scoliosis"	Commonly referred to as a "dowager's hump," kyphosis is an unnatural curving of the upper back that creates a hunchback appearance in the posture. It is rare to have pure kyphosis or pure scoliosis; usually there is a combination (kyphoscoliosis) with one component more remarkable than the other.	People with PWS often have hypotonia (low muscle tone) which can result in poor posture that may contribute to kyphosis. Exercises targeted to strengthen back muscles may help correct and/or limit the curvature. Surgery may be an option in severe cases. **See "Kyphoscoliosis" for more detailed intervention information.**	

Check Box if Symptom Exists	Symptom Name	Symptom Description	Intervention/Medication/ Support	Additional/Specific Instructions
☐	Kyphoscoliosis See also "Kyphosis" and "Scoliosis"	Kyphosis is an unnatural curving of the upper back that creates a hunchback appearance in the posture. Scoliosis is a lateral (sideways) curvature of the spine. Scoliosis and kyphosis are common symptoms. It is rare to have pure kyphosis or pure scoliosis; usually there is a combination, kyphoscoliosis, with one component more remarkable than the other.	People with PWS often have hypotonia (low muscle tone) which can result in poor posture that may contribute to kyphosis, scoliosis or both. Exercises targeted to strengthen back muscles may help correct and/or limit the curvature. Surgery may be an option in severe cases. People with PWS balance themselves differently; they tend to keep their head out more forward and have an increased kyphosis. If attempting to correct kyphosis to "normal" there is a high likelihood the surgery will fail, with the patient still flexing forward but peeling away from their spine hardware. **Infants and Children:** Do not have babies sitting up independently until they can pull themselves up to that position. Otherwise, babies tend to slump into a hypotonic position which we believe activates kyphoscoliosis. Rather, have infant sit in a chair inclined about 60° and emphasize tummy time. Get first screening spine film upright sitting when the child can reliably sit by themselves (usually 12-18 months); continue at least yearly for the first 4 years. Exercise is *extremely* important; therapeutic horseback riding is an important adjuvant. Casting for the very young, or bracing may be prescribed to correct or limit the curvature. If possible, delay surgical options until age 6 or 7 years. Use a "growth friendly" or expandable implant to allow child to grow while maintaining spine as corrected as possible.	
☐	Lying, Confabulation	Lying to avoid blame, telling untrue and sometimes elaborate stories that the individual may believe are true, inflating one's abilities or skill set. A common symptom in persons with PWS.	While honest most of the time, many persons with PWS will lie without use of logic or reasoning to avoid blame, especially but not limited to food acquisition. Some people may tell elaborate untrue stories to gain attention or for no apparent gain.	
☐	Metabolic Abnormality	Poor utilization of calories leading to obesity if uncontrolled. Medications, vitamins and supplements are metabolized slowly.	Provide healthy foods that contain necessary vitamins and minerals within a low calorie diet. Restrict access to unauthorized food. Medications should be started at low doses and increased slowly and with caution.	

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☐	Muscle Tone See also "Hypotonia"	The tension in muscles, even when in a relaxed state. Hypotonia is the medical term to describe low muscle tone. It is at times incorrectly confused with the amount of muscle. or weakness	Low muscle tone (hypotonia) in newborns with PWS results in poor sucking and a “floppy” posture. Beyond infancy, hypotonia may lead to poor posture, varying degrees of spinal curvature, problems with balance, coordination, and sensory integration skills. Increase strength to compensate for hypotonia through assuring adequate physical activity.	
☐	Obsessions & Perseveration	Continuous, repeated, undeterred focus on a particular topic, issue, or person that can interfere with the flow of the day. Attempts to restrict someone from their obsession may result in exaggerated emotional responses and extreme anger.	Anxiety can contribute to obsessions and perseveration. Reduce stressors that are causing anxiety. Behavioral strategies can help to mitigate: • Adhere to the schedule and routine; minimize change. When change needs to occur, prepare individual in advance when possible. • After answering a question 3-4 times, remind the individual the question has been asked and answered, then ask them to answer their own question. • Psychotropic medication may help reduce symptoms. • Care providers are encouraged to be patient and maintain a sense of humor especially with this symptom.	
☐	Pain Sensitivity	Patients with PWS can have a very high tolerance for pain and the severity of their symptoms may be overlooked. Patients are often poor at localizing pain. Sensitivity to pain may be diminished or absent, even in severe injuries or internal medical condition. There is often bruising or swelling for reasons unknown to the patient.	All injuries should be reported to and carefully assessed by the caregiver. Elevate and apply ice to injuries as needed. Individual may require examination by a physician to rule out injury, fracture or other health problem.	
☐	Poisoning - Accidental	Persons with PWS may eat spoiled or rotten foods, or items they believe are food but are poisonous such as ice pack filling, large quantities of alcohol, etc.	Because persons with PWS usually lack ability to vomit, gastric suction, known as stomach pump may be necessary. Emergency rooms should be made aware of the decreased ability to vomit. Vomiting can signal a life-threatening situation. Caution is advised using Syrup of Ipecac which can increase poisoning.	
☐	Psychosis	Disruptions to a person's thoughts and perceptions that make it difficult for them to recognize what is real and what isn't. Psychotic symptoms include visual and/or auditory hallucinations and occur more frequently in persons with UPD subtype.	Reduce environmental stressors. When using any psychotropic medication, start with a low dose and increase dosing slowly; metabolism is generally much slower in persons with PWS which means medication stays active in the body longer.	

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☐	Reflux	Gastroesophageal reflux (GERD), also known as acid reflux, is a condition where stomach contents come back up into the esophagus. Severity may be increased in infants with hypotonia. Decreased ability to vomit is a feature of PWS. Less common in PWS is rumination, the voluntary regurgitation of gastric contents.	After eating a meal, avoid lying supine (back position); instead prop at a 30 degree incline. Emergency rooms should be made aware of the decreased ability to vomit. Because the ability to vomit is often absent, vomiting can signal a life-threatening situation. Medications to treat reflux may be helpful.	
☐	Repetitive Behavior	Repetition in movement and/or thoughts. Examples may include repeatedly putting things in containers such as backpacks, etc. and then taking them out. Repetitive behavior can be characterized and measured using the Repetitive Behavior Scale-Revised (RBS-R).	For people with PWS, high levels of anxiety are common and contribute to repetitive behavior. Work to reduce the stressors causing anxiety. Behavioral strategies and/or psychotropic medications may be helpful. Care providers are encouraged to be patient and maintain a sense of humor especially with this symptom.	
☐	Respiratory Disorder	Any condition that inhibits breathing.	Treat the underlying cause.	
☐	Saliva Disorder-Dry Mouth	Most individuals with PWS have low saliva production. The result is dry mouth symptoms including thick, sticky saliva that will often appear as a thick white foam around the mouth. Dry mouth can adversely affect dental health, interfere with swallowing, and affect speech.	Use dry mouth products to stimulate saliva and reduce symptoms (e.g., over the counter ACT toothpaste or prescription pilocarpine (Salagen) or cevimeline (Evoxac). Teeth should be brushed frequently. Provide adequate fluoride to prevent dental decay. Biannual dental visits are recommended.	
☐	Scoliosis See also "Kyphosis"	Scoliosis is a lateral (sideways) curvature of the spine. Scoliosis is a common symptom of PWS. It is rare to have pure kyphosis or pure scoliosis, usually there is a combination (kyphoscoliosis) with one component more remarkable than the other.	People with PWS often have hypotonia (low muscle tone) which can result in poor posture that may contribute to scoliosis. Exercises targeted to strengthen back muscles may help correct and/or limit the curvature. Surgery may be an option in severe cases. **See "Kyphoscoliosis" for additional, more detailed intervention information.**	
☐	Self-Injurious Behavior	Many people with PWS engage in skin picking but can also engage in cutting, hair pulling, nail biting, burning, rectal picking, etc. Bruises, cuts, open sores and scars are common and can lead to false allegations of physical abuse.	One pilot study and anecdotal reports from parents show that the supplement N-acetyl cysteine (NAC) has been effective in reducing or eliminating skin picking. SSRI medications have sometimes been effective to reduce symptoms. Insect repellant, wearing long sleeves and pants when person is outdoors help to prevent bug bites and other irritants that can lead to skin picking. See also "Skin Picking."	

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☐	Sensory-Motor Integration Problems	Due to low muscle tone, individuals with PWS often experience problems integrating all senses: visual, tactile, auditory, vestibular, and proprioceptive systems. Symptoms typically look like sensitivity to tags, seams, hats; decreased balance; impaired depth perception.	Treatment generally consists of Sensory Integration Therapy, with particular focus on integrating the visual, tactile, vestibular, and proprioceptive systems.	
☐	Sexual Development Disorder	Both males and females with PWS experience hypogonad ism, disrupted function of sex hormones, and decreased fertility/infertility. Without sex hormone therapy, sexual maturity does not fully develop.	Refer to an endocrinology specialist. Testosterone may be prescribed for boys to increase penile development, voice deepening, and body hair. Estrogen therapy may be prescribed for girls to increase breast growth and induce regular menstrual cycles. Some endocrinologists may prescribe sex hormone therapy to improve bone strength especially when the patient is not treated with growth hormone therapy. Sex hormone therapy helps "normalize" body form and may provide a greater sense of "normalcy" within the peer group which can improve self esteem.	
☐	Skin Picking	Skin picking (Excoriation Disorder) is the repetitive and compulsive picking of skin which results in tissue damage. This can include nose picking, hair pulling, nail biting and removal, and rectal digging. Can be worse during times of stress or boredom.	Skin picking often increases during stress. Implementation of and adherence to PWS environmental management strategies is essential; contact PWCF and PWSA for educational materials. Behavioral treatments include diversion to alternative activity, frequent application of antibacterial ointment, keeping nails short, using protective dressings. Supplements such as N-acetyl cysteine (NAC), and psychotropic medications such as Topamax, SSRIs can be helpful. Closely monitor for skin picking post surgery; surgical site infections or dehiscences (wound rupture) occurs frequently from skin picking and may require protective bandages or braces to limit accessibility.	
☐	Sleep Disorder-Cataplexy	A sudden loss of muscle tone triggered by intense emotion. In PWS, often triggered by food consumption. Symptoms range from slurred speech to total body collapse.	Medications used to treat narcolepsy are often used to treat cataplexy, including Provigil (modafinil), Nuvigil (armodafinil).	

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☐	Sleep Disorder-Hypersomnia	Excessive daytime sleepiness.	Seek a possible underlying cause, such as sleep apnea or medications causing drowsiness. Most hypersomnia in PWS is of unknown cause. Treatment may consist of CPAP, BiPAP, caffeine, or medications including methylphenidate (Ritalin), modafinil (Provigil) or antidepressants such as fluoxetine (Prozac), citalopram (Celexa), paroxetine (Paxil) or sertraline (Zoloft). Sodium oxybate (Xyrem) may help treat excessive daytime sleepiness associated with narcolepsy.	
☐	Sleep Disorder-Narcolepsy	Extreme tendency to fall asleep during any type of activity at any time of the day. Frequently occurs in relaxed surroundings in persons with PWS.	Medication is usually necessary. Ritalin helps to reduce excessive daytime sleepiness and improves alertness. Other medications include Provigil (modafinil), Nuvigil (armodafinil). Sodium oxybate (Xyrem) may help treat excessive daytime sleepiness associated with narcolepsy.	
☐	Slow Bowel	Slow moving bowel causes constipation and/or diarrhea. Common in PWS. Diarrhea symptoms may indicate severe constipation.	Adequate water intake; daily exercise; osmotics to keep stool soft, making elimination easier, including: • First try dietary changes such as prunes, increased fluids, etc • Polyethylene glycol (Miralax) • Lactulose (Kristalose) • Magnesium citrate • Magnesium hydroxide (Milk of Magnesia). **DO NOT use Imodium or Pepto-Bismol to treat diarrhea as these may lead to bowel necrosis or rupture and cause death.**	
☐	Swallow Problems	Swallow dysfunction may be a contributor to morbidity in PWS. Food particles do not always clear the esophagus. Choking is a common symptom. Aspiration may be common wherein particles of food or liquid enter the lungs which may be lead to pneumonia.	All care providers should know how to administer the Heimlich maneuver. Cut food into smaller pieces. Remind individual to eat slowly. Use the "Sip & Chase" intervention: small sips of liquid following bites of food may help clear the esophagus.	
☐	Temperature Regulation Disorder	Due to dysfunctions in the central nervous system, the range of body temperature can vary significantly without apparent cause. Hypothermia (low body temperature) and hyperthermia (high body temperature) can easily occur and be life-threatening. Hyperthermia has been known to occur after receiving anesthesia. **Fever may be absent despite serious illness or infection.**	Know the patient's baseline temperature, which typically runs lower than the general population. hyperthermia, heat exhaustion and heat stroke require immediate medical attention. Treat hypothermia immediately by warming the individual with blankets and seek medical attention.	

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☐	Theft	Theft of both food and non-food items is common due to impulsivity and lack of judgment regarding consequences. Theft of money to be used to purchase food is common.	Especially for the individual known to take items, continuous supervision is required.	
☐	Thyroid Disorder-Hypothyroidism	Occurs when the thyroid gland is underactive. Can cause weight gain, fatigue, weakness, slow growth, dry or course hair, rough or pale skin, cold intolerance, muscle cramps or aches, constipation, irritability and/or depression. May be a cause of prolonged hypotonia in infants. Occurs at any age and is found in 15% of people with PWS.	Thyroid function tests are recommended in all patients. Thyroid disorders are typically well-managed with medication.	
☐	Unreliable Self Reporting	Due to altered /diminished pain awareness, or factitious disorder, suggestibility or medication seeking.	Always assess for actual illness or injury.	
☐	Vitamin(s) Deficiency	Lack of vitamins because of dietary deficiency. Low levels of vitamin C, vitamin D, and calcium contribute to decreased bone mineral.	Treat with vitamins and supplements.	
☐	Wandering	The person strays into unsafe territories and may be harmed. The most dangerous form of wandering is elopement in which the person leaves an area and does not return.	Continuous monitoring.	
☐	Other:			
☐	Other:			
☐	Other:			
☐	Other:			

Physician's Signature: _____ **Date:** _____

Physician's Contact Info/Stamp:

For more information about Prader-Willi syndrome or to request PWS Behavior Management protocols or a PWS Behavior Management Training contact the Prader-Willi California Foundation or the Prader-Willi Syndrome Association (USA)

Prader-Willi California Foundation 310-372-5053 | info@pwcf.org | www.pwcf.org
Prader-Willi Syndrome Association (USA) 800-926-4797 | info@pwsausa.org | www.pwsausa.org

pwcf.org Prader-Willi California Foundation
Supporting People with Prader-Willi Syndrome

Prader-Willi SYNDROME ASSOCIATION (USA)
SAVING AND TRANSFORMING LIVES